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An exploratory study of psychiatric symptoms in intellectually disabled people with and without a known history of sexual abuse

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COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: _____ Date: _____

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In loving memory of my dad, one of the greatest people I have ever known,
for your continual support, belief and love.

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ABSTRACT

Current research shows that people with intellectual disabilities display psychiatric symptoms which are often similar to those found in the general population. Furthermore, some literature has found that psychiatric difficulties in the intellectually disabled population can manifest in atypical forms which differ from those exhibited in the general population. The aim of this study was to explore the prevalence of psychiatric symptoms in the intellectually disabled population in South Africa. This particular study formed part of a larger project looking at trauma in a sample of intellectually disabled people. The PAS-ADD Checklist, which consists of two sections, was administered to a sample of caregivers of intellectually disabled people with and without a known history of sexual abuse. The data was analysed using non-parametric statistical tests. The first section of the instrument focused on the potentially traumatic life events that were reported by the caregivers and it was found that the group of individuals with a history of sexual assault had experienced more of these in comparison with the control group. The second section consisted of statements which were designed to elicit psychiatric symptoms on three subscales namely, possible organic condition, affective or neurotic disorder and psychotic disorder. The results showed that the total sample had a fairly high overall prevalence rate of psychiatric symptoms. In particular, the group with a History of Sexual Abuse obtained significantly higher scores on the affective/neurotic subscale when compared with the control group. There were also significant differences between the groups on the organic condition with the History of Sexual Abuse Group showing a higher prevalence of symptoms. The groups also differed on the psychotic disorder with the group who had a History of Sexual Abuse obtaining a higher score, although this was not statistically significant. The implications of the findings suggest that people with an intellectual disability who have a History of Sexual Abuse display an increased rate of psychiatric symptoms, particularly on the affective/neurotic spectrum. Whilst the findings generated from this study are in line with much of the international literature around the relationship between potentially traumatic life events and a high prevalence of affective symptoms in the intellectually disabled population, there is still a dearth of research in this area in South Africa.

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CHAPTER 1: INTRODUCTION

Living with a mental illness or an intellectual disability impacts on a person's life and their family in various ways. Significant cognitive impairment is involved with intellectual disability and it manifests early in an individual's life (Leonard, Peterson, De Klerk, Zubric, Glasson, Sanders & Bower, 2005) as cited in Kock (2008). Society has often been found to view people with intellectual disability in ways that could be described as patronizing, ridiculing and disregarding which leads to them often internalizing these attitudes and results in contributing to low self esteem (Allington-Smith, Ball & Haytor, 2002). Although up until the 1980's it was generally not considered that people with intellectual disability experienced mental illness, this view has shifted and the field of intellectual disability is one which has garnered an increasing amount of research attention internationally in the last few decades. Having to manage a dual diagnosis in which both mental illness and intellectual disability (hereafter referred to as ID) arise is thought to further complicate matters and when this diagnosis is made in an area that is under researched, the picture becomes even more complex.

Dagnan and Waring (2004) highlighted the relationship between stigma and psychological distress and suggested that the social interactions which people with ID experience with others play a pivotal role. In particular the development of core negative self-beliefs by individuals with ID is closely associated with feeling different which is described as a process through which individuals internalize stigmatization. The recognition by an individual with ID of being stigmatized is thought to negatively impact on their psychological well being (Dagnan & Waring, 2004). Issues of stigmatization and segregation are often present for people with ID in that they live in a world in which they are often excluded or called on to make adaptations in order to fit into the mainstream. Aman (1991) (as cited in Levitas & Gilson, 2000) describes people with ID as forming a subculture set apart from the general population in that its members grow up in mainstream families and homes, but mature along a different developmental track with a different developmental endpoint than that observed in mainstream culture.

Internationally, policies have been formulated encouraging the process of normalization, which refers to the integration of people with ID into the mainstream society and this has led to the expansion of special education and family support services (Dykens, 2006). Deinstitutionalisation forms a large part of the process of normalization and it refers to the transition of an individual from an institutional setting back into the community (Nottestad & Linaker, 1999). It was thought that institutions exacerbated psychiatric illness and that by moving people out of them, these difficulties would disappear. However research conducted by Nottestad and Linaker (1999) found that the opposite was true and that the psychopathology remained highly prevalent in the ID population after they moved back into the community. Locally, with regards to special education, although the South African Government has instituted a policy requiring the gradual transition into an integrated, inclusive education system, a local study conducted by Molteno, Molteno, Finchilescu and Dawes (2001) that looked at children with ID in Cape Town found that this legislation was not being practically supported and the majority of children with ID were noted to be attending special non-mainstream schools.

Aim of the study

The present research study is descriptive in nature and it attempts to focus on the ID population which has been relatively unexplored in South Africa. It aims to gain some indication of the prevalence of mental illness in a sample of people with ID including some individuals who have a history of sexual assault within a South African context. As no research has focused on this particular area, this exploratory study will highlight a much under-researched area and thus offer a starting point for further studies.

Structure of the thesis

The thesis begins with an introduction to the topic and the relevance of the research undertaken in this study. Chapter 2 starts with a discussion of the terms pertinent to the research and goes on to discuss issues related to research in the ID population. This is followed by a look at assessment-related issues which include a brief review of some of the most recent diagnostic classificatory systems. The varying ways in which the construct of prevalence is used in research is discussed and its relationship to levels of

ID, age and gender is highlighted. The association between traumatic life events and psychopathology is outlined and this is followed by a look at some of the diagnostic issues in the field of ID. The relationship between ID and specific disorders is discussed and the chapter ends with a consideration of the theoretical explanations underpinning ID as well as the aim of this study.

Chapter 3 focuses on the methodology which was used in the study. The study is contextualised and a brief discussion around the aim of the study is given. The particular research design which was chosen is then discussed and this is followed by a description of the sample and the participant's demographic details. The choice of instrument which was used in the study is outlined and its validity and reliability are discussed. The procedure that was followed in conducting the study is then discussed. The method which was used to analyse the data is then focused on and the chapter ends with a consideration of ethical issues.

Chapter 4 provides the results of the statistical analysis of the data. An explanation outlines how the results will be presented. Section 1 of the PAS-ADD Checklist looks at the life events experienced by the participants in each of the groups and highlights some of the trends which were found between the groups. The discussion then looks at Section 2 and the prevalence of psychiatric symptoms which were found across the sample. The statistical analysis which was used to obtain this information is explained. The overall trends across the three thresholds are discussed and this is followed by a closer examination of some of the more significant questions which highlighted differences between the two groups.

Chapter 5 offers a discussion of the results obtained from the statistical analysis and concludes the study. In particular it attempts to garner the results and provide varying explanations as to the reasons underlying the outcomes. It offers an understanding of the implications of this research within a South African context and concludes the study by focusing on the limitations of the methodology as well as the barriers to and implications for further research.

CHAPTER 2: LITERATURE REVIEW

In this chapter, a review of the prominent literature in the field of intellectual disability and mental illness is presented. To begin, the definitions of concepts and principles pertinent to the research are discussed. Following on from this, the central issues in the field of intellectual disability will be highlighted and a discussion will focus on research and assessment issues. This is then followed by a discussion looking at the relationship between the prevalence of psychiatric symptoms/disorders and various constructs, namely level of ID, age and gender. The arena of diagnostic issues is then discussed and the link between ID and specific disorders is looked at. Lastly, the theoretical explanations for ID are considered and the impact of life events is highlighted. The chapter concludes with a summary of the literature and a brief discussion of the aim of this study.

2.1 Definitions

Before reviewing the literature, it is essential to provide definitions of the important overarching terms that are pertinent to this research. These terms include intellectual disability, psychiatric illness and dual diagnosis. Intellectual disabilities are referred to in both the Diagnostic and Statistical Manual of Mental Disorders-Text Revision (DSM-IV TR) (APA, 2000) and the International Classification of Diseases –10 (ICD 10) (WHO, 1996) under the term Mental Retardation. In the United Kingdom, intellectual disability is referred to as learning difficulties and in parts of Ireland as mental handicap. The term mental retardation was first coined by the American Association on Mental Deficiency in the early 1960's and was based on a person's level of social functioning and the perception that they were not able to live independently as an adult (Greenspan & Switzky, 2003). Subsequent to this, after the development of the first intelligence test by Binet and Simon in 1910, the concept of mental retardation was defined and diagnosed according to one's score on a formal intelligence test. Underlying these approaches to defining intellectual disability was an overwhelming view that the source of difficulty lay within the individual (Leonard & Wen, 2002). Subsequently, criticism arose around the

intelligence quotient test being used as the sole basis for diagnosing a disorder which had initially been characterized as one of social incompetence and there was a move towards using multiple diagnostic criteria. Deficits in adaptive behaviour became an essential part of the diagnostic decision-making (Greenspan & Switzky, 2003). In this way, the focus shifted to the interface between the individual and the environment. Alongside the move towards creating a more inclusive definition, was a focus on developing a term which was not pejorative, as the term mental retardation was considered to be. The term intellectual disability is widely used internationally and held to be a more respectful and inclusive term (Greenspan & Switzky, 2003) and as such will be used in this thesis when describing this particular population.

It is also interesting to note that whilst the term mental retardation implies a static and unchangeable course, the term intellectual disability makes room for a more variable course which may include change (Meservy, 2008). Intellectual disability can be defined as a significantly below average level of general intellectual functioning, accompanied by significant limitations in adaptive capability (APA, 1994). Central to these different terms and definitions of ID is the presence of deficits in both intellectual functioning and adaptive behaviour. There is also an acceptance that these functional deficits are arranged into four categories indicated by intelligence quotient (IQ) scores of 70 or below on reliable, valid and appropriately standardized psychometric assessment instruments (Carr, 2006). The following ranges are used in DSM-IV TR for sub-classification of ID by level of intellectual functioning: mild: IQ level 50-55 to 70, moderate: IQ level 35-40 to 50-55, severe: IQ level 20-25 to 35-40 and profound: IQ level below 20-25 (Carr, 2006).

Cooper, Melville and Einfeld (2003) state that the term psychiatric or mental disorder is often used to indicate the presence of psychopathology. According to Einfeld and Aman (1995; as cited in Cooper et al., 2003) psychopathology is regarded as being evident with the presence of behaviour and emotions that are described as abnormal in terms of their qualitative or quantitative deviance. This occurrence is not deemed to be solely attributed to developmental delay, and it impacts significantly on the individual, carers or community. According to Kishore, Nizamie, Nizamie and Jahan (2004), the concept of

dual diagnosis has been in use in the field of psychiatry for a lengthy time period. This term was first used in relation to ID in the United States of America in the 1970's (White, Chant, Edwards, Townsend & Waghorn, 2005) and refers to the co-existence of an intellectual disability and a psychiatric disorder or mental health problem (Sturme, Lindsay & Didden, 2007; Dudley, Ahlgrim-Delzell & Calhoun, 1999). Related to ID and psychopathology are a variety of pivotal issues that span the areas of both research and diagnosis within the field of ID. The field of ID has only been brought into focus in the last few decades. As a result, a considerable amount of research has highlighted issues which have led to opposing viewpoints and contradictory findings amongst researchers. A general discussion will look at pertinent issues in both the research and diagnostic spheres and the impact of these on the concept of prevalence will be expanded upon.

2.2 Research-related issues in ID

There has been much debate about the existence of psychiatric difficulties in people with ID (Nezu, 1994). ID in itself is an area which is multifaceted and this is further complicated when introducing psychopathology into the picture. As recently as the 1980's it was still believed that people with ID did not have the cognitive capacity to experience mental health problems and any behavioural disturbances were solely attributed to the ID (Smiley, 2005). In Deb, Thomas and Bright (2001) two conceptually opposing views of the relationship between ID and psychiatric difficulties were put forward. The one view maintained that people with ID were protected from certain intellectual and psychological stress because of their impaired intellectual understanding and as such were less prone to developing psychiatric illnesses, whereas the other view suggests that they are in fact more vulnerable to psychosocial stress than people without ID and are therefore more prone to developing psychiatric symptomatology.

The majority of the research in the ID population group has been done internationally and appears to confirm the latter view, although some studies provided contradictory findings which will be discussed later in the chapter. Within the field of psychology, for a large portion of this century, the psychodynamic perspective has arguably been touted by some as a particularly influential force in applied psychology (Matson & Sevin, 1994). Some

therapists within this orientation queried whether psychiatric illness could occur in people with ID because of the deficits in their intellectual functioning and the abnormal development of their ego functioning (Matson & Sevin, 1994). This perspective impacted markedly in the research arena where studies were predominantly focused on researching and understanding the general population, as people with ID were not considered as experiencing psychiatric difficulties. Historically in the United States of America, this group was regarded as occupying a low status in the mental health arena and this has been carried through in the minimal didactic focus on ID in training psychologists, which has left professionals with limited knowledge of the difficulties that the ID population experiences (Matson & Sevin, 1994; Nezu, 1994).

In the South African context, ID is an issue that is marginalized within the broader mental health sector (Lund, Kleintjies, Campbell-Hall, Mjadu, Petersen, Bhana,...Flischer, 2008). For example, there are no local statistics available about the number of people with ID within the Cape Metropole (Molteno, 2008, personal communication), and few studies have been conducted locally on the presence of psychiatric conditions in this population. There is a reliance on international studies to help guide dual diagnosis in this population because of the lack of local research. Making use of international findings, although helpful, is somewhat circumscribed in its applicability in this country and does not contribute to expanding our knowledge base on the presentation and prevalence of mental illness in the intellectually disabled population in the South African setting. An issue which plays a huge role in defining ID and in marking a starting point from which many clinical decisions are made is that of assessment.

2.3 Assessment-related issues

Assessment has been used in the general population in order to provide information about an individual's functioning and it is seen as serving many purposes (Foxcroft & Roodt, 2001). Underpinning assessment in the general population is a focus on the cognitive functioning of an individual, with the construct of intelligence often measured in order to obtain an intelligence quotient which is then used as the basis from which to extrapolate

information about the person's functioning. The use of traditional assessment in the field of ID has generated much controversy as there is a great deal of diversity within the population of adults with ID. It includes those with a mild disability who often require low supports and stretches along a continuum to those with a more profound disability who have more complex support needs (White et al., 2005). Research has tended to focus on the mild ID population, often making use of assessment instruments used in the general population (McBrien, 2003). The influential role of culture and its impact on language is not always sufficiently accounted for in the assessment process and this is of fundamental importance when working with groups from diverse backgrounds. Research on the more severe levels of ID has been limited and it was only in 2001 that a classification system called the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC-LD) was created (Cooper et al., 2003). The advent of this diagnostic system will be discussed further as part of diagnostic issues in ID.

According to Leonard and Wen (2002), epidemiological studies generally ignore adaptive functioning in favour of using IQ scores as the single criterion in defining ID. Focusing solely on the cognitive functioning of an individual with ID does not give an indication of all the psychosocial aspects which may give rise to the onset of a psychiatric illness as well as the manner in which it presents itself (Dosen, 2005). According to Luis and Jansen (as cited in Foxcroft & Roodt, 2001), the assessment of people with ID is conducted for the purpose of being able to design and place them in training programmes that can optimize their potential. In this context, the role of the environment and in particular the interaction between the individual and the environment is considered. Apart from assessment, a great deal of research in the ID population has focused on prevalence.

2.4 Prevalence of dual diagnosis in intellectually disabled people

Studies suggest that the construct of prevalence is used in varying ways which impacts on the degree to which research findings can be compared, which in turn has implications for epidemiological research (Leonard & Wen, 2002). Using epidemiological principles in the study of ID provides information on how common ID is in the community as well

as if there has been a shift in the prevalence rates over a period of time. It also identifies instances where prevention may be possible and if a particular intervention has evidenced an influence on prevalence rates (Leonard & Wen, 2002). Some studies have differed in that they have measured either the point prevalence or lifetime prevalence of psychiatric symptoms and disorders. The point prevalence is sensitive to the presence of disorders which have a course characterized as involving relapses whilst the lifetime prevalence focuses on the continuous presence of disorders with a chronic course which are likely to have a consistent presence over time Deb et al. (2001). Whitaker and Read (2006), in their review of the literature looking at prevalence rates in adults, found that the majority of studies did not specify the type of prevalence that they reported on, which contributed to considerable differences in findings between studies using point and lifetime prevalence. The concepts of true prevalence and ascertained prevalence Roeleveld et al. (1997; as cited in Leonard & Wen, 2002) have also been used in some of the literature. True prevalence refers to “the total number of mentally retarded people in a population” and the ascertained prevalence to “the number of cases recorded by the authorities” (Leonard & Wen, 2002, p.120). In a great deal of research access to an entire population is often limited and as such research samples are often drawn from groups of individuals who are available for recruitment for research purposes and this often results in findings of ascertained prevalence rates.

The construct of prevalence is interlinked with various factors which influence research findings. Epidemiological studies which looked at mental health problems in people with ID have produced very different and often contradictory results (Smiley, 2005). There are many shortcomings in the literature which provide reasons for the differences in prevalence rates across studies (O’Brien, 2002). The increased prevalence of a dual diagnosis may in part be explained by some studies incorporating behavioural problems and autism into their definition of psychiatric disorders and as such may be overly inclusive in providing a wider definition of psychiatric disorders than studies which do not include these diagnoses, both of which are common among people with ID (Deb et al., 2001; Whitaker & Read, 2006). Some of the other reasons that underlie the differences in prevalence rates across studies include differences in assessment

procedures, definition of ID, tools and the sampling methods used (Kishore et al., 2004). Most prevalence studies of mental illness in people with ID make use of institutionalized and out-patient psychiatric populations which provide samples that are likely to have a higher percentage of people with a psychiatric disorder than would be the case in the whole ID population. In such an instance, these samples cannot be considered to be random (Deb et al., 2001; Smiley, 2005). In a large proportion of studies, administrative samples were used as opposed to direct contact with the client and these studies appeared to generate higher prevalence rates than those in which the examination of the client was part of the study (Whitehead & Read, 2006). However, although the studies conducted make use of different methodologies which may produce varying results concerning the prevalence rates of different disorders, there is consensus that psychiatric disorder is common in people with ID (O'Brien, 2002; White et al., 2005).

Literature has revealed contradictory findings when comparing the prevalence rates of psychiatric illness in the general population with that of people with ID. Some research that has compared the intellectually disabled population with the general population found that people with ID are at markedly higher risk for psychopathology or dual diagnosis (Matson & Sevin, 1994; Borthwick-Duffy, 1994; Smiley, 2005; Dykens, 2006). In contrast, Deb et al. (2001) research findings suggest that when making use of criteria used in the general population (ICD-10) in a sample of adults with mild-moderate ID, the overall rate of functional psychiatric illness was similar to that found in the general population. Similarly, Whitaker and Read (2006) reviewed epidemiological studies on psychiatric disorder in people with ID (in community settings) to ascertain whether the prevalence is higher in the ID population and if it applies to people with ID as a whole or just to particular subgroups. They found that there were no outstanding indicators that the prevalence of psychiatric disorders in people with mild ID was any higher than in the normal population as a whole. It is thought that in the case where ID is considered synonymous with mental illness, this may lead to a tendency to over-diagnose, with the opposite being true that if it is believed that people with ID are immune to mental health problems, this may lead to under-diagnosis (Kishore et al., 2004). It is also important,

when looking at prevalence rates, to consider how these are influenced by factors like level of disability, age and gender, which are discussed briefly in the next subsections.

2.4.1 Prevalence and levels of ID

Studies examining the prevalence of mental health problems across differing levels of ability have produced conflicting results (Smiley, 2005), in some studies higher rates of psychiatric disorder have been found in people with mild ID as opposed to those with severe and profound disability but this could be because it is more difficult to identify and diagnose a psychiatric disorder according to standard diagnostic criteria in people with severe and profound ID (Smiley, 2005). In contrast, Whitaker and Read (2006) found no convincing evidence that the overall rate of psychiatric disorders for adults with mild ID (IQ levels 50-70) was any higher than that for the general population. It is important to note that particular etiological factors such as epilepsy, physical disability and sensory impairment are more prevalent in the more severe levels of ID and are thought to play a role in contributing to an increased prevalence of psychiatric disorders in this subgroup (Smiley, 2005).

2.4.2 Prevalence and age

In looking at studies on children, Emerson (2003) found a higher prevalence rate of some psychiatric disorders in children with ID compared to children without. A review of studies investigating the prevalence of psychiatric disorders in children found evidence that the rate of psychiatric disorder is higher in children with ID than those without (Whitaker & Read, 2006). Other commonly reported disorders that were found in children without ID included pervasive developmental disorders, depression, anxiety and behavioural disorders which included disruptive and antisocial behaviour. In particular, the prevalence rates of depression were not significantly different between children with and without ID, whilst the rate of anxiety disorders and problematic behaviours were considerably higher in children with ID when compared to their counterparts in the general population (Whitaker & Read, 2006). The review also revealed evidence supporting the notion that the greater the degree of ID, the higher the rate of mental

disorder. Emerson (2003) found in particular that the rates of conduct disorders, anxiety disorders, attention deficit hyperactivity disorders and pervasive developmental disorders was higher amongst children with ID compared to those without, although his findings reported no statistical significances between children with and without ID with regards to the rates of depressive disorders, eating disorders or psychosis. Molteno et al. (2001) conducted a study looking at the behavioural and emotional problems of a sample of children with ID in the Cape Metropole. Their findings indicated that there was a higher prevalence of behavioural difficulties in children with severe to profound ID and that 31% of the sample was considered to have a dual diagnosis. Interestingly, the first study conducted on the prevalence of ID and associated disabilities in rural children in South Africa was done by Christianson, Zwane, Manga, Rosen, Venter, Downs & Kromberg (2002) and it was part of a larger study looking at specific childhood disabilities but it did not include a focus on psychiatric symptoms.

The literature focusing on the relationship between prevalence and ageing has produced inconsistent findings. According to Torr and Davis (2007), mental health problems in older people with ID is similar to that found in younger adults with ID. However a higher rate of dementia and physical health problems was found to be associated with an increase in age. In contrast, Deb, et al. (2001) found that increasing age and the presence of physical disability were significantly associated with the occurrence of psychiatric illness. According to Smiley (2005), some factors such as physical health problems and an increase in sensory deficits and the cumulative effect of life events are associated with ageing and are likely to increase the prevalence of psychiatric illness in older people.

2.4.3 Prevalence and gender

Gender differences in psychopathology have been noted in research in the general population (APA, 1994; Smiley, 2005) but research in this area in the field of ID has received little attention, apart from studies on depression. Research conducted on the general population has suggested findings that women are more likely to exhibit a higher rate of affective and anxiety disorder and men a higher rate of psychosis (Smiley, 2005). A study by Hastings, Hatton, Taylor and Maddison (2004) on a sample of people with ID

using the Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD) Checklist found a significantly increased rate of affective and neurotic symptoms in women compared with men, which is akin to findings in the general population. A study by Tsakanikos, Bouras, Sturmey and Holt (2006) also supported the notion that there are gender differences in psychopathology in the ID population. In particular, they found that there were higher rates of adjustment disorder and dementia in women and an increased rate of personality disorders among males. Having discussed issues related to research findings on the prevalence of psychiatric problems in people with intellectual disability, the next section looks at diagnostic issues as they pertain to ID.

2.5 Diagnostic issues

The practice of diagnosis is useful in that it guides decision-making in clinical care, service provision and is used extensively in the research arena (Cooper et al., 2003). As has been previously mentioned, research has historically focused on the general population and made use of instruments which have been specifically designed for this population. These instruments, such as the DSM-IV TR (APA, 2000) and the ICD-10 (WHO, 1996) are internationally agreed upon amongst researchers as a universal means of measuring and diagnosing psychiatric illness in the general population. According to Deb and Weston (2000), the full spectrum of mental disorders among the ID population has been seen but the establishing of a diagnosis has been particularly challenging because there is no formal psychiatric diagnostic classification system for people with ID (Benson, 2004). There are several diagnostic issues that have an impact on identifying a psychiatric illness in a person with ID. Cooper (2003) notes that in the field of ID, there is some debate around the process of diagnostic classification and some have argued that diagnosing an individual labels them which fosters stigma, whilst others debate the advantages that diagnosis provides in terms of clinical management and service delivery.

2.5.1 Diagnostic tools

A large proportion of research has pointed to a lack of appropriate assessment and diagnostic tools for use with the ID population (Deb & Weston, 2000; Cooper et al.,

2003; Sturmev et al., 2007). Whilst Sturmev et al. (2007) noted that a number of screening instruments have been developed since the 1980's specifically for use with people with ID, subsequent research has indicated varying quality in these instruments and ultimately a lack in a gold standard diagnostic tool for use in the ID population. Classification systems used in the general population are often held to be unsuitable for use in the ID population because of their reliance on the subjective reporting of symptomatology (Smiley, 2005; Cooper et al. 2003). Some studies have however made use of generalized classification systems to detect a dual diagnosis in individuals with mild mental retardation but findings have indicated that they have not been suited to use with individuals who function at lower levels (Deb & Weston, 2000; Smiley, 2005). Establishing a diagnosis in the more severe levels of ID focuses more predominantly on concrete behaviours as people with this level of ID are likely to exhibit major cognitive and communication difficulties (Deb & Weston, 2000; Holden & Gitlesen, 2004).

In 2001, the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (hereafter referred to as DC – LD) was developed as a new system of classifying psychiatric disorders in adults with ID (Cooper et al., 2003). The DC-LD was created through a collaborative process driven by psychiatrists in the United Kingdom and the Republic of Ireland. The ICD-10 manual was used as a basis upon which the DC-LD criteria were drawn up (Melville, 2003). Its use is recommended as a complement to the ICD-10 and the DSM-IV TR when diagnosing psychiatric illness in people with mild ID but may be used as a sole classification system for people with moderate to profound disabilities (McBrien, 2003). Although the DC-LD has been developed with the aim of providing a diagnostic classification system for use in the ID population which would also facilitate research (Cooper et al., 2003), it is still a new system and further research into its usefulness and limitations is required before it is accepted as the gold standard for diagnosing psychiatric illness in the ID population (Cooper et al., 2003). In the United States of America in 1998, a similar collaborative effort between the National Association for the Dually Diagnosed and the American Psychiatric Association (APA) began, which has now resulted in the development of a similar diagnostic classification system to the DC-LD,

called the Diagnostic Manual – Intellectual Disabilities: A Textbook of Diagnoses of Mental Disorders in Persons with Intellectual Disabilities (DM – ID). (Ninnivagi, 2008) (as cited in Fletcher, Loschen, Stravakiki & Kingston, 2008) highlights that the DM-ID is considered to be complementary to the DSM-IV TR (APA, 2000) with a specific focus on providing guidelines for making diagnoses in the ID population.

2.5.2 Maladaptive behaviours as diagnostic equivalents

Differing views amongst researchers on the presence of maladaptive behaviours and their relationship with psychiatric disorders have been noted in the literature (Hemmings, Gravestock, Pickard & Bouras, 2006; McIntyre, Blacher & Baker, 2002). Whilst on the one hand, maladaptive behaviours have been used as behavioural equivalents for standard psychiatric diagnostic criteria (Hurley, 2006; Matson, Gonzalez, Terlonge, Thorsen & Laud, 2007), others have argued that behavioural disturbance is not necessarily dysfunctional (Allen & Davies, 2007). It is possible for an individual with ID to display behaviour such as overt aggression in the absence of any form of psychiatric disturbance or even to present with a psychiatric disorder without any significant behavioural challenges. The potential for the co-morbid presence of both conditions also exists (Allen & Davies, 2007). Part of the disparity in the research is due to the uncertainty around the nosology of problem behaviours (Cooper, Smiley, Finlayson, Jackson, Allan, Williamson, Mantry & Morrison, 2007), as challenging behaviours are not listed in the DSM-IV TR (APA, 2000) as a psychiatric disorder, but they have been included in a number of studies and appear to increase the prevalence rates in several studies (Whitaker & Read, 2006).

Challenging behaviours are often what prompt a referral to an organization and as such are an important occurrence to note. It appears that in childhood that the overall prevalence of problem behaviour increases with age, reaching a peak between ages 15-34 years and then declining (Smiley, 2005). According to Smiley (2005) there appears to be a strong correlation between an increased prevalence of problem behaviour and the severe levels of ID. However, it should be noted that people with more profound levels of ID generally experience greater levels of restricted mobility which means that they are

less likely to exhibit outwardly directed behaviour. Moss et al. (2000; as cited in Whitaker & Read, 2006) found a strong association between an increased severity of challenging behaviour being linked with an increased prevalence of psychiatric symptoms as measured in the PAS-ADD Checklist. In line with this, research by Hemmings et al. (2006) looked at research findings of studies using the PAS-ADD Checklist and noted that psychiatric symptoms were significantly increased in those with problem behaviours.

The presence of maladaptive behaviour may be seen as an example of diagnostic overshadowing, which further complicates diagnosis in ID people. The term diagnostic overshadowing was coined by Reiss and colleagues in the 1980's (Bailey & Andrews, 2003) and describes the phenomenon of how the presence of an intellectual disability is foregrounded to the extent that even when an individual with ID exhibits symptoms of abnormal behaviour which may be indicative of a psychiatric disorder, these symptoms are instead incorrectly attributed solely to the intellectual disability (Dudley et al., 1999). It is suggested that diagnostic overshadowing occurs in two ways, firstly when the features of intellectual disability are so prominent that clinicians do not notice features of an additional psychiatric disorder and secondly, when features are noticed but are incorrectly attributed to being part of the intellectual disability rather than as a separate psychiatric disorder (Bailey & Andrews, 2003). Some research has also referred to the concept of pathoplasty when describing the relationship between ID and psychiatric illness. Cooper et al. (2003) describes the pathoplastic effect of ID as when the severity of the person's ID affects the symptomatology and alters the way in which a psychiatric disorder is manifested. The presence of pathoplasticity is evident in some symptoms, such as guilt not presenting and in others such as aggression or the exacerbation of other problem behaviours occurring frequently.

2.6 ID and specific disorders

The prevalence rates of psychiatric disorders in the ID population vary widely between 10% and 39% (Deb et al., 2001; Borthwick-Duffy, 1994). As discussed under diagnostic issues, these variations in findings are thought to result from methodological problems.

The following discussion looks at the prevalence rates of some of the more common psychiatric disorders that have been researched in the ID population and compares this with prevalence rates in the general population.

Research suggests that the prevalence of epilepsy is higher in the ID population when compared with the general population (Matthews, Weston, Baxter, Felce & Kerr, 2008). This is thought to be due to 'congenital or acquired neurological deficits generally found in people with ID' Burke et al. (1999; as cited in Matson, Bamburg, Mayville & Kahn, 1999, p. 531). Bowley and Kerr (2002; as cited in Matthews et al., 2008) indicate prevalence rates ranging from 20% to 30%. A large proportion of the studies have focused on children with ID and this restricts the generalisability of their findings to the adult population (McGrother, Bhaumik, Thorp, Hauck, Branford & Watson, 2006). According to Scheepers and Kerr (2003), epilepsy contributes to an increased risk for disturbances in emotional, perceptual and cognitive spheres in comparison to other chronic illness. It is interesting to note that in a study by Matson et al. (1999) individuals who had ID and epilepsy displayed more deficits in social and adaptive skills in comparison with individuals who had ID but no history of epilepsy. Although some studies found an increased rate of psychiatric symptoms in individuals with seizures, epilepsy in itself was not a risk factor for psychiatric disorder (Smiley, 2005). A higher prevalence rate of epilepsy was however associated with an increased severity of ID (McGrother et al., 2006).

According to Hurley (2006), there is a growing recognition that mood disorders in the ID population may present with an atypical clinical picture such as aggression, increased self – injury and irritability, which is noted to be commonly reported (Smiley & Cooper, 2003). As previously discussed, although some research has focused on using maladaptive behaviours as behavioural equivalents when diagnosing psychiatric illness, some have opposed this approach especially when diagnosing depression (Hurley, 2006). Although people with ID share the risk factors that the general population does when it comes to depression, it is thought that individuals with ID may be further disadvantaged because of their limited coping skills and experiences of discrimination and segregation

(Smiley, 2005). According to O'Brien (2002) the majority of studies on depression in the ID population have looked at symptoms corresponding to Major Depressive Disorder and by implication it is thought that symptoms like motor slowing and social withdrawal are more likely to be overlooked, although they are also indicative of depressive symptomatology. McBrien (2003) expanded on this and suggested that maladaptive behaviours, temper tantrums, self-injury, loss of daily living skills, irritability and somatic complaints are also likely to be indicative of depression. In a study by Cain, Davidson, Burhan, Andolsek, Baxter, Sullivan, Florescue, List and Deutsch (2003), it was noted that bipolar disorder was poorly recognized and not readily diagnosed in individuals with ID. Their research suggested that apart from the expected symptoms, individuals who met a diagnosis for bipolar disorder also displayed other atypical behaviours such as "...teasing, intrusiveness, aggression and self – injury" (Cain et al., 2003, p. 38). Matson, Gonzalez, Terlonge, Thorson and Laud (2007) estimated the prevalence of bipolar disorder as being higher in the ID population in comparison with the general population but also noted the diagnostic challenges of this disorder in the ID population.

Identifying anxiety disorders in people with ID is often difficult. In the population of people with more severe levels of ID, behavioural symptoms are often the only available source on which to base an assessment which often results in misdiagnosis (Smiley, 2005). The diagnostic picture is further complicated by the fact that anxiety often presents in various different psychiatric disorders (Bailey & Andrews, 2003). Although minimal research has been done on the diagnosis of specific anxiety disorders in the ID population, certain behavioural phenotypes such as Fragile X syndrome has been associated with symptoms of social anxiety (Bailey & Andrews, 2003; Smiley, 2005) and Williams syndrome with symptoms of generalized anxiety (Smiley, 2005).

The majority of the research literature on psychotic disorders focuses on people with mild ID, in comparison to psychosis in people with severe to profound ID. Cooper et al. (2007) state that it is almost impossible to diagnose psychotic disorders in people with more profound ID as their severely limited communication skills make it difficult to clarify the

subjective experience of delusions and hallucinations. It is recognized that there is an increased prevalence of psychotic disorder in people with ID compared with the general population and this is a consistent finding in the literature (Smiley, 2005). The prevalence rates of Schizophrenia are considered to be higher in people with ID when compared with the general population (Deb et al., 2001; Bouras, Cowley, Holt, Newton & Sturmey, 2003). A prevalence rate of Schizophrenia in 3% of the ID population was reported compared with 1% in the general population (Melville, 2003).

The majority of research focusing on personality disorders in people with ID has made use of diagnostic measures used in the general population and incorporated standardized measures created for the ID population (Moreland, Hendy & Brown, 2008). The prevalence rates of studies vary considerably and highlight the difficulties in diagnosis. With regard to many of the diagnostic criteria of personality disorders, it is apparent that there is often a considerable overlap between personality disorders and ID. This is especially apparent in dependent personality disorder where the criteria focusing on having difficulty with making everyday decisions without excessive input from others and needing others to adopt responsibility for the major areas of the individual's life (DSM-IV TR, 2000) often form part of the definition of ID.

Autism is often found to exist alongside ID (Tsakanikos et al., 2005). As previously discussed, research suggests an increased prevalence of psychiatric illness in the ID population (Deb et al., 2001) but it is not clear whether having a diagnosis of both ID and autism increases an individual's susceptibility to a psychiatric disorder. It has often been suggested that people with autism are more vulnerable to certain psychiatric disorders. Research conducted by Tsakanikos et al. (2005) found a higher rate of depressive disorders in adults with ID and autism compared to adults with ID but without autism. Although a higher rate of depression was noted, there was no other evidence in this study of increased rates of psychopathology in people with a diagnosis of ID and autism. In contrast, a study by Bradley, Summers, Wood and Bryson (2004) found an increased rate of psychopathology among individuals with a diagnosis of severe ID and autism when compared with those without a diagnosis of autism.

In O'Brien's (2002) review of research findings on Attention Deficit Hyperactivity Disorder (ADHD) it was found that most studies focused on children and that little was known about hyperactivity among adults with ID, although it is suggested that there may be qualitative differences between hyperactivity in the ID population when compared with the general population. Matson and Sevin (1994) also offer a suggestion that there is a high prevalence of ADHD in males with Fragile X syndrome.

The subject of addictions in the ID population is not well researched and most of the studies have focused on the epidemiology rather than controlled research looking at etiology, prevention and treatment of addiction in ID (McGillicuddy, 2006). The findings from these surveys suggest that adolescents and adults in the ID population abuse substances to a slightly lesser degree than the general population (McGillicuddy, 2006). Although early literature noted a relationship between alcohol misuse and ID, more recent research indicates that prevalence rates of alcohol misuse are similar to that found in the general population (Deb & Weston, 2000).

2.7 Theoretical explanations

There are a variety of theories around the causes of dual diagnosis. These varying perspectives have generated research from which some theoretical developments have occurred (Matson & Sevin, 1994). Organic, behavioural, developmental and sociocultural models offer different ways of understanding dual diagnosis and the choice of theoretical model guiding any study will influence the way in which the research findings are generated. A brief discussion of the organic and developmental models will be followed by a more detailed one of the socio-cultural model. This will be followed by a presentation of the life events that are held by this model as central to the development of psychiatric symptoms in people with ID.

2.7.1 Organic models

Organic models of psychopathology emphasise biological and genetic causes and the presence of structural brain abnormalities in a person with ID is thought to increase their

risk of mental illness (Matson & Sevin, 1994). Within the ID population specific genetic disorders have been associated with specific patterns of psychopathology (Matson & Sevin, 1994). A great deal of research has focused on autism and emerging evidence points to an increased prevalence of affective disorders in individuals with a dual diagnosis of ID and autism (Tsakanikos et al., 2005). Likewise, a strong relationship has been established in individuals with Down syndrome and their vulnerability to developing Alzheimer's disease (Matson & Sevin, 1994). As previously mentioned, the literature has also found associations between Fragile X syndrome and social anxiety (Smiley, 2005) and Lesch Nyan syndrome and its link with overeating (Matson & Sevin, 1994). As can be deduced from the above research findings it is clear that organic etiologies offer some evidence as to the possible underlying biological contributions to psychiatric illness in the ID population although there are other models which provide varying explanations.

2.7.2 Behavioral models

The behavioural models of psychopathology hold that a person develops a behavioural repertoire through interacting with the environment. It is thought that the environments in which many people with ID work and reside are often characterized by limited opportunities to develop social skills and low rates of positive reinforcement which may contribute to depression (Matson & Sevin, 1994). Seligman's theory of learned helplessness was used as a context to understand the relationship between inappropriate punishment and psychopathology in people with ID. It describes how a sense of helplessness is learned when a person is continually exposed to negative stimuli regardless of their behaviour, which results in the person subjectively experiencing that they are unable to exert any form of control in their environment. This in turn is thought to result in symptoms of depression (Matson & Sevin, 1994). Social learning theory has been applied in understanding the development of fears and phobias in the ID population and proposes that individuals with ID develop phobic behaviours that stem from events that were initially modeled (Matson & Sevin, 1994).

2.7.3 Developmental models

According to the developmental model, people with ID develop according to the universal patterns of cognitive development but at much slower rates than the normal population and ultimately reach a lower level of cognitive functioning (Zigler & Bennett-Gates, 1999). Therefore, this model looks at understanding the meaning of behaviour in relationship to the person's developmental level (Matson & Sevin, 1994; Dosen, 2005). In understanding the development of psychopathology in people with ID, an individual's behaviour is understood by taking account of their developmental level. During the diagnostic process, the developmental approach examines the individual's level of emotional and personality development as part of the assessment process (Dosen, 2005). Matson and Sevin (1994) suggested that the high prevalence of depressive symptoms, fears and phobias in people with ID is similar to individuals at comparable levels of development, for example with children. Any development of an individual will always unfold within a context and as such sociocultural models also offer perspectives on understanding how psychiatric illnesses emerge.

2.7.4 The socio-cultural model

This model looks at the social context and holds that many people with ID are exposed to a high number of negative social experiences (Matson & Sevin, 1994). Furthermore, it is postulated that people with ID are in fact aware of these negative social realities and that this, in combination with a reduced capacity to withstand stress, makes them more vulnerable to developing psychiatric illness (Matson & Sevin, 1994). This is especially apparent in that people with ID are often separated from many normal experiences as their caregivers attempt to protect them from ridicule (Matson & Sevin, 1994). Another socio-cultural factor that impacts on the emotional well-being of people with ID is that of de-institutionalisation. This often involves the reintegration of a person from an in-patient setting into the community where the individual is likely to encounter daily life stressors and an increasing likelihood of exposure to failure experiences which could precipitate emotional distress (Matson & Sevin, 1994). The section below will look at the occurrence

some of potentially traumatic life events and their contribution to the development of psychiatric difficulties in the ID population.

‘A life event has been defined as an experience or event with an established origin and short duration, which can be related to a person’s psychological condition’ according to Goodyear (p.248, 1996, as cited in Esbensen & Bensen, 2006). In the general population, a relationship between experiencing traumatic life events and this resulting in psychopathology has been noted (McCarthy, 2001). This is not the case in the field of ID in which relatively few studies have looked at the impact of life events on the mental health of people with ID (Tsakanikos, Bouras, Costello & Holt, 2007). It is thought that people with ID are particularly vulnerable to challenging life events (Tsakanikos et al., 2007) and although early studies looked at the impact of single events, recent research has moved towards focusing on the impact of exposure to multiple traumatic and stressful life events on those with ID (Tsakanikos et al., 2007). Hamilton, Sutherland and Iacono (2005) found some associations between psychiatric problems and life events experienced by adults with ID but these associations were shown to vary among sub-groups of this population. In a study conducted by Tsakanikos et al. (2007), it was found that depression, personality disorder and adjustment reaction were associated with difficult or challenging life events. In a study by Hastings et al. (2004) focusing on life events using the PAS-ADD Checklist, it was found that in individuals who had experienced one or more life events in the year preceding the interview scored above the threshold on the affective/neurotic subscale of the PAS-ADD, which suggests that there is a relationship between being exposed to traumatic life events and experiencing affective symptoms. Of particular interest in this study is the impact of sexual abuse on individuals with ID and its potential contribution to psychiatric illness.

Sexual abuse

Literature which focuses on sexual abuse in the general population strongly suggests that there is an impact on psychological functioning (Watkins, 1990). Burnham et al. (1988; as cited in Watkins, 1990) found that there was a higher prevalence rate for particular psychiatric disorders in individuals who had been sexually assaulted compared with those

who had not. In particular, depression, mania, drug abuse and anxiety disorders were found to be significantly more prevalent in individuals who had experienced a sexual trauma and it was also noted that these disorders were also found to increase the likelihood of an individual being sexually assaulted (Watkins, 1990). Of interest is the finding that regardless of age, experiencing a sexual assault is associated with negative effects, but that this it is even more pronounced if the sexual assault occurs in childhood (Watkins, 1990). This point is significant in that the ID population is particularly vulnerable and their mental age may reveal similarities in terms of the way in which children and ID individuals may process a trauma.

Research by Sequiera, Howlin and Hollins (2003) who studied the impact of sexual abuse on individuals with ID also found that experiences of sexual abuse were associated with increased rates of mental illness and behavioural problems. Their findings indicated that although individuals with ID experience similar psychological reactions to sexual abuse as those observed in the general population, there was an increased rate of stereotypical behaviour (repetitive rocking and odd or bizarre behaviours) which was unique to the ID population. Some of the other consequences of sexual abuse that are reported in people with ID include an increase in post-traumatic stress symptoms (APA, 2000), low self-esteem, challenging behaviours, depression, self-blame, self-harm and relationship problems (Peckham, 2007).

It is thought that in South Africa, where high levels of crime are experienced, that there exists a strong probability that the general population is likely to experience a traumatic event in their life-time. It is further thought that the vulnerability of people with ID places them in an even more susceptible position to experiencing some form of traumatic event which in turn is thought to increase the likelihood of psychiatric symptomatology. In a recent local study which looked at the relationship between sexual assault and PTSD in a sample of individuals with ID it was found that individuals who had been sexually assaulted presented with significantly more PTSD symptoms (Jasson, 2009). Another local study confirmed the exacerbating effect of sexual assault on challenging behaviour in individuals with ID (Kwendakwema, 2009) and highlights the similarities between

local and international findings regarding the damaging impact of traumatic life events on individuals with ID and their resulting contribution to psychiatric illness.

2.8 Chapter summary

This literature review has focused predominantly on international research and its findings and compared these with the South African context. It is evident that internationally, a great deal of focus has developed towards the ID population. This can be seen in the increase in research in the field of ID and in the developments in both the United Kingdom and the United States of America, of diagnostic classification systems specifically for use in the ID population. Although this has been coupled with a trend towards developing some assessment measures specifically for use in the ID population, a lack of consensus still remains around many of the pivotal diagnostic issues, which in turn impact on the ways in which research is conducted and limits the ability to compare research findings. In contrast, in South Africa, the same trend has not been seen and local research in this area has been minimal. It is hypothesized that the status of the ID population locally is still being observed in a similar fashion to how it was understood in the early years internationally prior to the current research impetus and it is thought that research on the ID population in South Africa will gradually adopt the international trend towards a more inclusive acknowledgement of minority populations.

2.9 Aims of study

This present research study aims to look at the prevalence of dual diagnosis in a sample of people with ID. As it includes a sample of people with ID who have a history of sexual assault it also attempts to understand if there is an association between having a history of sexual assault and the subsequent development of psychiatric symptoms.

CHAPTER 3: METHODOLOGY

This chapter focuses on the methodology which guided this research study. The research project is contextualised and the aim of the research is briefly discussed. This is followed by looking at the rationale for the use of the particular research design. Various aspects of the research process are discussed, including the procedures that were followed in recruiting and interviewing participants as well as the instrument that was used. The process of data analysis is described in depth and this is followed by a consideration of ethical issues pertinent to the research.

3.1 The research project

This particular study forms part of a larger multi-method research project that is investigating trauma in people with ID. In an attempt to isolate or identify symptoms or problems that are particular to sexually abused people with ID, a cohort sample of ID people with no known history of abuse was included as a control group. The larger project is a collaborative partnership between the University of Cape Town and Cape Mental Health Society (CMHS), which is a non-governmental organization that looks after the needs of psychiatric and intellectually disabled individuals living in various communities in the Cape Town metropolitan area. CMHS has a client base of about 2000 individuals, of whom approximately 70% have an intellectual disability.

3.2 Aim of the study

The aim of the research was to investigate the prevalence of dual diagnosis in a sample of people with ID with and without a known history of sexual assault. It was a descriptive study that focused on groups that already exist in the population. The sample was divided into two groups and the incidence of psychiatric symptoms in each of the groups was explored. As there are no local studies which have looked specifically at the prevalence of a dual diagnosis in the ID population, this study sought to obtain an indication of this within the South African context. It was hypothesised that participants with ID who had experienced a traumatic sexual assault would present with a higher prevalence of psychiatric symptoms when compared with a group of participants who had not

experienced a sexual trauma. It was also hypothesised that the majority of the psychiatric symptoms that would be exhibited would fall within the affective/neurotic spectrum as international research suggests that mood disorders are the most frequently observed psychiatric disorders in the general population, particularly amongst women (Astbury & Cabral, 2000; as cited in Lunskey, 2003).

3.3 Research Design

Conducting research in the ID population is complicated by the fact that people in this population often experience difficulties around recognizing and reporting symptoms. They often have to rely on assistance from others when accessing healthcare and the role of the caregiver is seen as being pivotal in this regard (Smiley, 2005). In line with this, it is noted that various screening tools designed to detect and elicit mental health problems, have been developed for use with caregivers of intellectually disabled people. It was thus decided to make use of an instrument which involved obtaining responses from a caregiver who was familiar with the participant. Examples of some of the instruments that have been used in prior research and which rely on caregivers responses are the Psychopathology Instrument for Mentally Retarded Adults (PIMRA), the Reiss Screen (Moss, Prosser, Costello, Simpson, Patel, Rowe, Turner & Hatton, 1998) and the Developmental Behaviour Checklist for Adults (DBC-A) (Mohr, Tonge & Einfeld, 2005).

In deciding on the type of research design for this study, a quantitative approach was favored over a qualitative one. Quantitative studies focus on numerical data and use this as a starting point to analyze probabilities whilst in contrast qualitative approaches tend to look for meanings in the data (Hayes, 2000). Furthermore, quantitative approaches produce results which can be replicated in future research and provide a platform for comparisons within and between studies (Hayes, 2000). Although quantitative methods have been used in research in the ID population, an absence of a universally agreed upon method of diagnostic measurement has led to varying prevalence rates being generated by different studies which makes comparison of the various findings difficult (Leonard &

Wen, 2002). Because research on issues of ID is relatively new, particularly in South Africa, this study is exploratory in nature.

3.4 Sampling

The participants who were part of this research consisted of two groups of caregivers of people who have been diagnosed with ID. The caregivers served as informants for the total sample of 54 intellectually disabled people by giving background information as well as providing responses to the PAS-ADD statements. The caregivers who participated in the research had different relationships with the ID individuals which were as follows, mother ($n = 18$), sister ($n = 5$), aunt ($n = 1$), grandmother ($n = 4$), sister-in-law ($n = 1$), foster parent ($n = 1$), caretaker ($n = 4$), friend ($n = 1$), workshop manager ($n = 3$), workshop supervisor ($n = 3$) and social worker ($n = 13$).

The sample was divided into two equal groups of 27 caregivers of intellectually disabled individuals. The first group consisted of caregivers of intellectually disabled people who had been sexually assaulted and who had been referred to CHMS for a psycho-legal assessment through the Sexual Abuse Victim Empowerment (SAVE) project. The participants in this group were included because they were available and were willing to participate in the study. The SAVE project only becomes involved in cases where an individual with an ID has experienced a sexual trauma and there is prosecution of the case. They undergo an assessment in order to determine their level of disability, ability to testify in court about the rape or sexual assault that they suffered as well as ability to consent to sexual acts.

The control group consisted of caregivers of people who were known to have an ID but who did not have any known history of rape or sexual assault. This group was a convenience sample that were selected to match the SAVE group as closely as possible in terms of demographics and living in similar communities. They were chosen by the social workers, who were the managing case-workers, from their case rosters. People with severe and profound levels of ID were excluded because communication and cognitive difficulties are often more difficult to overcome in the more severe levels of ID and there

are likely to be multiple difficulties which may be unrelated to mental illness (Moss, 2002). In addition, people with severe and profound disability were least likely to present in the SAVE programme because they were mostly unable to identify the perpetrators, which meant that there were no legal proceedings. Interviews and assessments with the caregivers of the group of people with a history of sexual abuse was conducted by two clinical psychology masters students and that with the caregivers of the control group were interviewed by seven social workers from CMHS.

3.4.1 Sample demographics

Although the respondents in this research were the caregivers, the demographic information of the individuals with ID whom the caregivers were responding about was outlined as below. An analysis of the demographics of each of the groups as seen in Table 1 showed that the mean age for the total sample of people with ID ($N = 52$) was 23.65 years, ($SD = 9.99$; range = 11–52 years). Ages were not obtained for 2 participants. A t -test for independent groups was conducted to compare the means between the two groups of subjects to see if the ages were similar. The mean age for the control group was 29.12 years ($SD = 10.82$; range = 11–35 years) which was considerably higher than the mean age of the History of Sexual Abuse Group of 18.59 years ($SD = 5.7$; range = 14–52 years). This indicated that there was a considerable difference in chronological age between the two groups. There were a higher number of females in comparison with males in both groups. While there were more people with mild ID in the control group, the History of Sexual Abuse Group had equal numbers of people in the mild and moderate ranges. This study also included the racial classifications of the ID individuals. It is noted that categorizing racial groups is a contentious issue, particularly within the South African context. For the purpose of this study, the term African was used to group individuals who were previously classified as Black. Similarly, the other racial categories were also indicated separately including Coloured, White and Indian. The racial composition in both groups showed a higher number of Coloured people in comparison with the other racial classifications. In the control group there were a number of individuals who were reported to be on medication with a slightly higher number in the group with a History of Sexual Abuse. There was a noticeable difference between the two

groups in terms of epilepsy with an absence of any history of epilepsy reported by the caregivers amongst the individuals in the control group when compared with the History of Sexual Abuse Group.

Table1 Demographics of the sample of participants

Demographic Details	Control Group (No known hx of sexual abuse) (n = 27)	Experimental group (Hx of sexual abuse) (n = 27)
Age		
Mean	29.12	18.59
Minimum	14.00	11.00
Maximum	52.00	35.00
Gender (n)		
Male	9	4
Female	18	23
Race (n)		
Coloured	18	16
African	3	6
White	1	2
Indian	1	0
Unknown	0	3
Degree of intellectual disability		
Mild	16	11
Moderate	7	11
Unknown	4	5
Medication (n)		
Yes	7	9
No	13	13
Unknown	7	5
Epilepsy (n)		
Yes	0	7
No	25	17
Unknown	2	1

3.5 Instrument

For this study, the Mini Psychiatric Assessment Schedule for Adults with Developmental Disability Checklist (PAS-ADD) (Moss, 2002) was used to screen the participants for psychiatric symptoms. The PAS-ADD Checklist was designed to assist in the detection and diagnosis of mental health problems in adults with an ID that is within the mild to moderate spectrum (Deb & Weston, 2000). The PAS-ADD was chosen because it has been field-tested on the full developmental spectrum in British learning disability (up to IQ 65) services (Hemmings et al., 2006) and has been used in most international studies that investigated mental illness in this population (Hemmings et al., 2006). A further consideration which influenced the choice of instrument is that because communication is often limited in people with ID, a carer-completed checklist provides an opportunity for the caregivers to convey their valuable insights and observations in a structured manner (Mohr et al., 2005). The questionnaire was translated and back-translated into isi-Xhosa and Afrikaans to ensure accuracy of the translated instruments.

The PAS-ADD Checklist consists of two sections: Section 1 of the instrument records potentially traumatic life events that the client may have experienced in the past two years, including death of a close family member, parental divorce and sexual problems. Section 2 consists of 25 statements describing problem behaviours noted in a given time period (over the last four weeks) and asks respondents to indicate whether these are present and to rate their severity on a 4-point scale. Section 2 includes items which are designed to cover particular Axis I domains namely, dementia, organic mental illness, schizophrenia, bipolar mood disorder and depression (Moss et al., 1998).

The PAS-ADD Checklist allows for the identification of a range of problems, all of which may be part of a psychiatric condition, and produces three scores relating to the presence and threshold of an Affective or Neurotic Disorder, a possible Organic Condition and a Psychotic Disorder. The broad symptoms encompassed in the three scales included, affective/neurotic disorder (changes in appetite and sleeping, restlessness, changes in ways of relating to others, loss of interest and change in affect); possible organic disorder (dementia-type symptoms such as a decrease in self-care skills

and being more forgetful or confused); psychotic disorder (strange behaviours and beliefs) (Hastings et al., 2004). (See Appendix B). The results that are generated provide an indication if a more thorough mental health assessment is required. It can also be used to monitor individuals over a period of time (Prosser et al, 1998).

The four-point scale was chosen as the best compromise, the even number of rating points avoiding the possibility of giving a non-committal middle rating (Moss et al., 1998). The actual scoring, which is given on the last page of the checklist and which clarifies the scoring and crossing of thresholds, is as follows,

- (1.) Total score 1: Affective or neurotic disorder
(maximum possible score = 28; threshold = 6)
- (2.) Total score 2: Possible organic condition
(maximum possible score = 8; threshold = 5)
- (3.) Total score 3: Psychotic disorder
(maximum possible score = 6; threshold = 2)

If an obtained score meets or exceeds the threshold, then this is used as an indicator for further clinical or formal psychiatric assessment (Taylor, Hatton, Dixon & Douglas, 2004).

3.5.1 Reliability and Validity of the PAS-ADD

The PAS-ADD has been independently investigated and found to have both reasonable reliability and validity when used as an assessment tool in the ID population (Prosser et al, 1998; Smiley, 2005). In terms of methodological considerations, the PAS-ADD Checklist has been found to be over-inclusive, which means that it has good sensitivity in detecting mental health problems and this is noted as being an important property for a screening instrument (Taylor et al., 2004). Currently, it is seen as one of the most useful tools in identifying and diagnosing psychiatric disorders in adults. The PAS-ADD Checklist is a screening tool and assists in the decision-making process around whether an individual requires a further psychiatric assessment (Smiley, 2005).

3.6 Procedure

Permission to conduct this study was sought from the ethics committee of the University of Cape Town as well as from Cape Mental Health Society.

History of Sexual Abuse Group

In terms of recruiting participants for the History of Sexual Abuse Group, two Clinical Psychology Master's students who were the chief researchers made telephonic contact and arranged appointments with those caregivers who were willing to participate in the research. During this initial contact with the caregivers, voluntary participation was emphasized and initial consent was obtained from the caregiver for the participant to be interviewed. It was also explained to the caregivers that participation in the research process was separate from the assessment process offered by the SAVE project.

The interviews were conducted by the two Masters students at the Child Guidance Clinic, which is part of the University of Cape Town, at the offices of CMHS or in the residential homes where the participants lived. The interviews lasted for approximately one and a half hours. At the outset of the interviewing process an explanation of the aim of the research was given to the ID individuals and their caregivers. Caregivers were asked to give written consent and assents were obtained from all the participants. In cases where it was possible written consent was also given by the participants. Ethical considerations were upheld by the researchers in that both the participants and their caregivers were assured of the confidential nature of the interview and that their details would at all times be kept anonymous. In being sensitive to the risk of re-traumatization, the interviewers informed the both the victim and the caregivers that if they became at all uncomfortable with anything that was being discussed during the interview that it could be brought to an end. They were also informed that they had the freedom to withdraw from the research at any stage without being disadvantaged in any way.

The interview process involved taking a short history from each caregiver about the participant which included questions around level of schooling, any history of epilepsy,

the use of chronic medication as well as details around the sexual assault that was experienced. Once a history was obtained, the questionnaire was administered to the caregivers in either English or Afrikaans. In order to maintain uniformity throughout the process, standardized instructions were given by the interviewers. After the interview was completed, caregivers were given R60,00 towards any transport costs incurred.

Control group

A group of seven social workers from CMHS interviewed participants in the control group. The process of interviewing the participants and their caregivers was similar to that undertaken in the History of Sexual Abuse group. The social workers were trained for the role of research assistants by the researchers who interviewed the History of Sexual Abuse group to ensure that the method of administration was accurate and standardized. In addition to this, inter-rater ratings were conducted between the interviewers across both groups to compare consistency in scoring. The interviews were conducted with a caregiver who was familiar with the particular participant's behavior and had the opportunity to observe them for a minimum of 6 months. A consent form (See Appendix A) accompanied each interview and voluntary participation in the research was emphasised. Interviews conducted with the caregivers lasted approximately one and a half hours and were done in the preferred language of the respondent. The interviews took place at the residential homes of the participants, supported accommodations, workshops and offices at CMHS. Caregivers were asked whether the participants had experienced any of the life events listed in the first section of the questionnaire and this was followed by asking them to answer 25 statements put to them using a 4-point scale (1 = Has not happened, or has always been like this, 2 = Happened occasionally or present in a mild form, 3 = Happened frequently, or present in a moderate form, 4 = Present in a severe form for much of the time).

3.7 Inter-rater reliability

The social workers who administered the checklist to the control group underwent training in an attempt to ensure uniformity in administration procedures as well as increasing the reliability between the interviewers of both groups. Due to the number of

interviewers involved in gathering the data across the two groups it was important to establish inter-rater reliability. The most crucial measure of inter-rater reliability is the extent to which raters agree on which individuals have scores which put them over one of the three thresholds (Moss et al., 1998). To gain an indication of inter-rater reliability amongst the masters students who were the main researchers, four interviews (14%) were done with both of the students being present. Consent was obtained from the participants for two interviewers to be present during the interview. Whilst the first interviewer administered the questionnaires the second interviewer observed the administration process and coded the questionnaires independently. The percentage agreement between the master's students was high, ranging from 84% - 98%.

To determine inter-rater reliability with the seven social workers, the two master's students conducted interviews with some of the participants from the control group who had been interviewed by the social workers. The percentage agreement between the researchers and the social workers ranged from 75% - 98%.

3.8 Data analysis

The data which was collected on the PAS-ADD Checklist was then captured and analysed using the statistical programmes Statistica version 9 and the Statistical Package for Social Sciences SPSS (PASW), version 18 software. The data distributions of the scores were examined in order to determine which method of analyses would be most appropriate. From this examination, it was noted that the data was not normally distributed and this guided the decision to use non-parametric tests. Non-parametric tests are used to determine the differences between the means of two groups and this kind of statistical procedure is favoured in instances where the sampling distribution is not assumed to be normally distributed (Field, 2009). The Mann-Whitney *U* test and the Chi-squared tests are non-parametric tests and were used to determine statistical significance.

The Mann-Whitney *U* test looks at two independent samples and the differences between them (Field, 2009). In particular it uses the median as opposed to the means and standard deviations in analyzing the data. The Mann-Whitney *U* test is limited to use with 2

samples. It was decided to use this because making use of the mean does not offer a good representation of the scores in the group. These tests were used to analyse the two groups responses on the life events in Section 1 of the checklist and to determine whether there were any statistical differences between the two groups. In particular, the life events of death and major financial crisis were statistically analysed in order to determine whether there was any statistically significant differences between the two groups responses. The Mann-Whitney *U* test was employed to calculate the prevalence rates of the three categories of psychiatric symptoms on Section 2 of the PAS-ADD checklist and to observe whether there were any significant differences between the groups. The effect sizes were calculated using Vargha and Delaney's *A* which is a measure of stochastic superiority and shows the probability of whether a score sampled at random from one distribution would be greater than or equal to a score sampled at random from another distribution (Vargha & Delaney, 2000). Vargha and Delaney's *A* was developed from McGraw and Wong's Common Language Statistic and allows for the effect size to be communicated more easily (Vargha & Delaney, 2000).

3.9 Ethical considerations

Obtaining informed consent from people with ID to participate in research presents particular ethical challenges in that the researcher needs to ensure that the potential participants are given information around the implications of being involved in the particular research as well as not being coerced into taking part (Cameron & Murphy, 2006). In this research, ethical approval was given by the University of Cape Town for the research to be undertaken and Cape Mental Health gave consent and made provision for the PAS-ADD to be administered by social workers to the caregivers of the ID participants.

Participation in this study was voluntary and no participant was forced to engage in the study nor were they disadvantaged in any way if they refused participation. Participants were required to give written consent after the purpose of the study had been explained. The participant's confidentiality and privacy was protected at all times and none of them are identified at any point in this project. The participants were already familiar with

CMHS and as the organization offers support to ID and psychiatric clients and it was decided by the researchers that if any participant became distressed during the research process, they would be referred to the managing social worker for support. In addition the organization could also offer follow up psychological support if that was found to be necessary.

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CHAPTER 4: RESULTS

This chapter reports on the results of the statistical analysis of the caregiver's responses obtained on the PAS-ADD Checklist. This will begin by looking at the responses obtained on the life events in Section 1 and will be followed by a closer look at the responses obtained by each group on the three subscales in Section 2.

4.1 Analysis of results

The findings obtained on the PAS-ADD Checklist were broken into two parts. The first section focused on the responses obtained on Section 1 of the checklist which were the life events. The second part looked at the results of Section 2 of the checklist, namely the behaviours, and highlighted significant differences between the two groups on each of the thresholds. Finally, each question in Section 2 was analysed in order to determine whether there were any significant inconsistencies between the groups.

Section 1 - Life events

In observing the responses to the questions on life events in the two groups (Table 2), a number of differences were apparent. The total number of life events that were reported by the control group was lower ($n = 58$) when compared with the History of Sexual Abuse Group ($n = 76$). The History of Sexual Abuse Group reported experiencing a higher number of deaths of first degree relatives and close others ($n = 12$) when compared with the control group ($n = 7$). There was also a marked difference in terms of the History of Sexual Abuse Group experiencing more financial crises ($n = 9$) than the control group ($n = 2$). Of particular interest is the number of sexual problems ($n = 13$) reported in the History of Sexual Abuse Group when compared with the control group ($n = 0$). Responses between the two groups were equal in the categories of serious illness or injury to self and alcohol and drug problems. It was also noted that the number of participants in the control group ($n = 5$) who reported that they had not experienced any of the potentially traumatic life events was considerably higher than in the History of Sexual Abuse Group ($n = 1$).

Table 2: Responses on Section 1 of the PAS-ADD Checklist

Life event	Control group (No hx of sexual abuse)	Known with a sexual abuse hx group
Death of a first degree relative	2	4
Death of a close other	5	8
Serious illness or injury	2	2
Retirement from work	1	0
Serious illness of a close other	6	4
Move of house or residence	6	4
Break up of a steady relationship	2	0
Separation or divorce	0	1
Alcohol problem	1	1
Drug problem	1	1
Serious problem with a close other	3	5
Unemployed or seeking work	3	5
Breakdown of relationship with parents	4	3
Laid off or sacked from work	0	3
Something valuable lost or stolen	1	0
Problems with police or other authority	4	3
Major financial crisis	2	9
Sexual problem	0	13
Any other event	10	9
None of the above events	5	1

A statistical analysis of the life events was conducted using the Mann-Whitney *U* test as well as two Chi-squared tests. These tests were used to determine whether there were any statistical significances between the two groups with regards to the responses on the life events of death and financial problems as well as the total life events experienced by each group. The Chi-squared tests results showed that although the History of Sexual Abuse

Group experienced more deaths than the control group, the difference between the two groups was not significant ($\chi^2(1) = 2.146, p = 0.143$). (see Table 3.)

Table 3. Chi-square test of life event: death

Chi-square test						
	<i>N</i>	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson						
Chi-square	54	2.146	1	0.143	0.241	0.120

Similarly, there was no significant difference between the two groups with respect to major financial crisis, although the History of Sexual Abuse Group reported a higher number of experiences of this than the control group ($\chi^2(1) = 0.164, p = 0.685$) (see Table 4).

Table 4. Chi-square test of life event: major financial crisis

Chi-square test						
	<i>N</i>	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson						
Chi-square	54	0.164	1	0.685	1.000	0.500

A Mann-Whitney *U* test was used to compare the distribution of the total average number of life events and the results showed that there was no statistically significant difference between the groups ($U = 0.241$).

Section 2 – Behaviours

4.2 Comparisons between the groups

The purpose of the analysis of the results from the PAS-ADD Checklist was to gain an indication of the prevalence of psychiatric symptoms in the total sample as well as to see

if there were any significant differences between the two groups used in this study. In looking at the two groups' responses on the PAS-ADD Checklist (see Table 5), in the History of Sexual Abuse Group more participants met the threshold in terms of displaying symptoms of a psychiatric illness in general, in comparison with those in the No history of Sexual Abuse Group who met the threshold criteria.

Table 5 Percentage of psychiatric symptoms between the groups

Groups	<i>n</i>	Overall % of psychiatric symptoms
Hx of sex abuse group	27	51.85%
No hx of sex abuse group	27	25.9%

A Mann-Whitney *U* test was done to compare the groups' scores on each of the three subscales (see Table 6). The findings generated indicated that there was a significant difference between the groups on both the affective/neurotic condition subscale ($U = 219.50, p = 0.01$) as well as on the organic condition ($U = 235.00, p = 0.02$) but that no significant difference was noted between the groups on the psychotic disorder subscale. In order to determine how much of an effect having a history of sexual assault had on developing organic and affective/neurotic conditions the effect size was calculated (see Table 4). This was done using the measure of stochastic superiority, Vargha and Delaney's *A*, which was developed from McGraw and Wong's Common Language Effect Size (Vargha & Delaney, 2000). Vargha and Delaney's *A* measures the chances that a randomly selected member from Group 1 (here 'Hx of Sexual Abuse') will have an equal or higher score than a randomly selected member from Group 2 (here No hx of Sexual Abuse). The three subscales of the checklist, affective/neurotic disorder, organic condition and psychotic disorder were used in this calculation. It was found on the affective/neurotic subscale that the History of Sexual Abuse Group had the same or higher score compared with the control group (see Table 6). Similarly on the organic condition, the History of Sexual Abuse Group had a 68% chance of having an equal or

higher score on this subscale in comparison with the control group. It was noted that on the psychotic disorder subscale that the groups were similar in that 57% of the History of Sexual Abuse Group had the same or higher score in comparison with the control group.

Table 6 Comparison of the groups on the subscales.

Mann-Whitney U Test						
	Rank Sum (Hx of sex abuse)	Rank Sum (No Hx of sex abuse)	U	Z	p - value	Effect Size A
Affective/neurotic Condition	887.00	597.50	219.50	2.49	0.01	69%
Organic Condition	872.00	613.00	235.00	2.23	0.02	68%
Psychotic Disorder	794.50	690.50	312.50	0.89	0.37	57%

4.3 Results obtained on the thresholds

The results of the responses obtained by each group on the three subscales of the PAS-ADD will be noted individually as follows,

4.3.1 Affective-neurotic subscale

Across the total sample, it was noted that the participants obtained a notably high overall score on the affective or neurotic disorder, with 31.48% of participants in all groups meeting the threshold criteria. In particular, there was a significant difference between the groups on the affective/neurotic subscale ($U = 219.50$, $p = 0.01$) with the History of Sexual Abuse Group obtaining a threshold score of 40.74% which was considerably higher than the control group's threshold score of 22.22%. (see Table 7).

Table 7 Affective /neurotic disorder

	<i>n</i>	Affective/neurotic disorder		Threshold (%)
		Mean	SD	
All Groups	54	4.38	4.97	31.48%
Hx of sexual abuse	27	5.92	5.31	40.74%
No Hx of sexual abuse (control)	27	2.85	4.15	22.22%

Significant questions on the affective/neurotic subscale

Subsequent to obtaining an indication of the two groups responses on the affective/neurotic subscale, a further analysis was conducted which looked at each individual statement pertaining to this subscale on the checklist in order to determine if there were any further significant variations between the two groups. (See Appendix C for a presentation of all the questions). The Mann-Whitney *U* test was used in order to establish any significant differences between the groups on specific questions. The affective/neurotic subscale consists of 20 statements and the result showed that between the groups there were significant differences ($p < 0.05$) detected on four of the 20 questions/statements. The four questions were as follows:

Q3 – Broken *sleep, waking up for an hour or more, before falling back to sleep*

Q8 – Increased *appetite, over-eating*

Q11 – Shows *loss of confidence with other people, such as repeatedly asking for reassurance*

Q12 – Suspicious, *untrusting, behaving as if someone is trying to harm them or is talking about them*

These four questions/statements form part of the statements that are grouped together when scoring the affective/neurotic disorder subscale on the PAS-ADD Checklist. The History of Sexual Abuse Group obtained higher scores on each of these four questions/statements in comparison with the control group (refer to Table 8). These findings are consistent with the threshold scores obtained in Table 4 as the History of Sexual Assault obtained significantly higher scores on the affective/neurotic disorder subscale of which these four questions formed part of, in comparison with the control group.

Table 8 Significant between-group differences in the questions of the PAS-ADD checklist

	Rank Sum - Hx of Sex Abuse	Rank Sum - Known with ID	U	Z	p - value	Effect size
Q 3	823.5000	661.5000	283.5000	2.262956	0.023639	61%
Q 8	837.0000	648.0000	270.0000	2.330781	0.019766	63%
Q 11	823.5000	661.5000	283.5000	2.069539	0.038496	61%
Q 12	837.0000	648.0000	270.0000	2.518863	0.011774	63%

4.3.2 Organic disorder subscale

In the total sample 16.66% of the responses met the threshold on the possible organic condition. There were significant differences between the groups on this subscale ($U = 235.00, p=0.02$) with more of the History of Sexual Abuse Group meeting the threshold criteria in comparison with the control group (see Table 9). This subscale consists of 12 statements on the checklist and the analysis did not reveal any significant differences between the group's responses on these particular statements.

Table 9. Responses on the Organic disorder subscale

Organic disorder				
	<i>n</i>	Mean	SD	Threshold
All groups	54	2.03	2.13	16.66%
Hx of sex abuse	27	2.62	1.94	18.51%
No Hx of sex abuse	27	1.44	2.18	14.81%

4.3.3 Psychotic disorder subscale

In the total sample, 9.25% of the responses met the threshold criteria on the psychotic disorder. The statistical analysis did not reveal any significant differences between the two groups ($U = 312.50, p = 0.37$) (see Table 10). The responses on the psychotic disorder subscale were lower in comparison with the scores on the other subscales but followed a similar pattern in terms of the History of Sexual Abuse Group obtaining a higher score than the control group. This subscale consists of 3 statements but the analysis did not reveal any significant differences between the two groups responses to these statements.

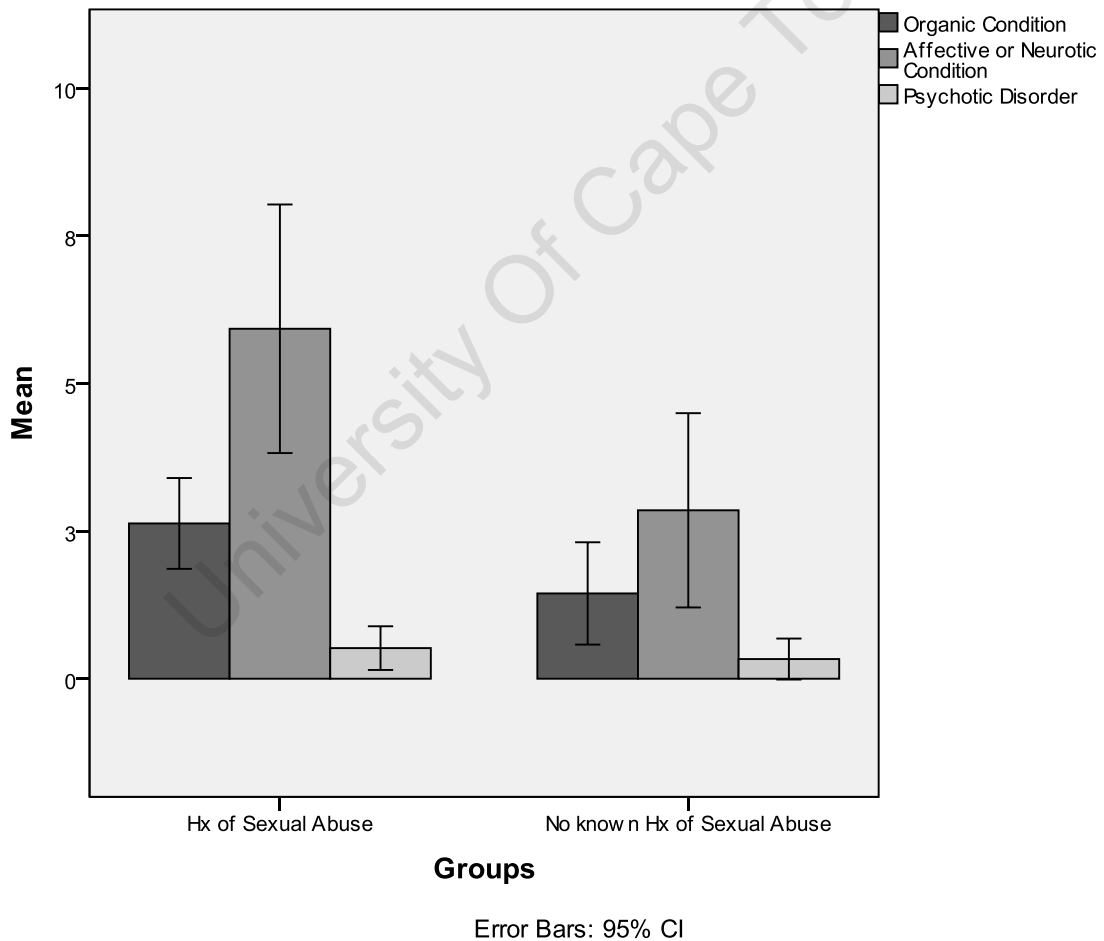
Table 10. Responses on the psychotic disorder subscale

Psychotic disorder				
	<i>n</i>	Mean	SD	Threshold
All groups	54	0.42	0.90	9.25%
Hx of sexual abuse	27	0.51	0.93	11.11%
No Hx of sexual abuse	27	0.33	0.87	7.40%

Graphic depiction of responses across the groups

Figure 1 shows the average scores obtained per subscale between the two groups. As was previously noted, the History of Sexual Abuse Group on average had a higher number of responses that met the threshold criteria for affective/neurotic disorders in comparison with the control group. Although the mean responses in the control group did not meet the threshold criteria it is interesting to note that the mean responses of both groups had a similar pattern across the three subscales with both groups obtaining average responses which were higher on the affective/neurotic subscale in comparison with the other two subscales.

Figure 1 Average score obtained by each group across the thresholds



4.4 Summary of results

In summary, the History of Sexual Abuse Group obtained significantly higher scores on the affective/neurotic and organic subscales in comparison with the control group. When looking at specific questions, it was noted that there were significant differences between the two groups on four questions which were part of the affective/neurotic subscale, with the History of Sexual Abuse Group scoring higher. These findings indicate that having a history of sexual abuse does have an impact on the development of psychiatric symptoms, particularly in the development of affective/neurotic symptoms.

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CHAPTER 5: DISCUSSION AND CONCLUSION

This chapter provides a discussion of the results that were reported in the previous chapter. It begins by looking at the relationship between life events, psychiatric illness and age. The findings from this study are then discussed and there is an attempt at understanding both groups of the sample's experiences of potentially traumatic life events in Section 1 and the possible link with psychiatric symptoms that the PAS-ADD Checklist revealed. This is then followed by a look at the responses to Section 2 of the checklist and the prevalence of psychiatric symptoms in the sample of the participants who met the threshold criteria. The chapter concludes with a look at the implications of the findings in a South African context.

5.1 Life events and psychiatric illness

In the general population the association between experiencing traumatic life events and a vulnerability to developing psychopathology is commonly reported (McCarthy, 2001; Emerson, 2003; Cooper et al., 2007). In addition, Hastings et al. (2004) argue that the opposite is also true in that individuals suffering from current psychological problems may also be exposed to a greater number of life events. In particular, depression, substance misuse, acute stress reactions, anxiety states and personality changes are some of the more frequent disorders that people suffer from as a result of traumatic ordeals (McCarthy, 2001). Whilst a large proportion of research in the ID field has looked at life events and their contribution in the development of maladaptive behaviour, the focus has only recently shifted to the role of life events in the trajectory of psychopathology in the ID population (Esbensen & Benson, 2006).

In looking at the responses in this study obtained on Section 1 of the PAS-ADD Checklist it is interesting to note that the History of Sexual Abuse Group reported experiencing a greater number ($N = 76$) of potentially traumatic life events in comparison with the control group ($N = 58$). On average, the History of Sexual Abuse Group experienced more life events ($n = 2.77$) when compared with the control group ($n = 1.96$). Earlier literature looked at the impact of single events and their relationship to

psychopathology, but of late, research has begun to look at the role of cumulative life events and their contribution to the development of psychiatric illness in people with ID (Tsakanikos et al., 2007). The higher rate of potentially traumatic events in the History of Sexual Abuse Group found in this study is in line with findings from a study conducted by Hastings et al. (2004), who reported that experiencing one or more life events was linked with an increased risk for affective disorder. Tsakanikos et al. (2007) similarly reported that being exposed to multiple life events was reliably associated with depression, personality disorder and adjustment reaction. Thus, the findings in this study show a similar trend indicating an association between multiple life events in intellectually disabled people and high scores on measures or subscales of the affective/neurotic disorder spectrum. It is important to note that any causal inference is made with caution and that further longitudinal research would be needed to support stronger inferences about a direct relationship between being exposed to multiple life events and a subsequent likelihood of experiencing psychiatric problems.

Significance of particular life events

While there appears to be a link between potentially traumatic life events and psychiatric symptoms, it is interesting that this association seems to vary with the nature of the life event. In this study, it is interesting to note that there are similarities as well as differences between the two groups responses on the life events section. Stein et al. (2008) found that South Africa has a predominantly high lifetime prevalence rate of substance use disorders in the general population which have an early age at onset in comparison with data from other countries. Whilst in this present study, the responses on the life events pertaining to the ID individuals drug and alcohol abuse was equal across both groups and fairly low, it is thought that this may be due to the small sample size as well as supported by research indicating that the people with ID abuse substances to a slightly lesser degree than the general population (McGillicuddy, 2006).

There was a difference in the responses to the life event of a major financial crisis with the History of Sexual Abuse group ($n = 9$) obtaining a higher number of responses in comparison with the control group ($n = 2$). It is thought that part of this could be

explained by the high number of deaths of caregivers that the History of Sexual Abuse Group experienced. It is likely that these caregivers were not only a source of emotional support but they also looked after the individuals financially and that their deaths have left the ID individuals in a financially vulnerable position. Although there are sheltered workshops available for people with ID, it may be that the high overall presence of psychiatric symptoms lessens the chances of these individuals being able to participate in these income-generating activities, which further increases the likelihood of them having to depend on others for financial support. Tsakanikos et al. (2007) noted that there was an association between a diagnosis of a personality disorder and a major financial crisis. It is also interesting to note that the control group had slightly higher responses ($n = 6$) to the life event of moving house or residence compared with the History of Sexual Abuse Group ($n = 4$), which differs somewhat from research by Tsakanikos et al. (2007) that showed that out of all the life events mentioned in the PAS-ADD Checklist, moving house or residence was most significantly associated with psychopathology.

Bereavement and psychiatric illness

Some life events, particularly those that involve loss are known to have a significant psychological impact on the affected individuals. A large proportion of the life events listed in Section 1 may be seen as being linked with a variety of losses, for example, of a significant other, a job, a relationship, an object etc. It is well known that people's reactions to a loss are often associated with grief. The death of a significant other is seen as a major life event and is thought to induce an intense and particularly difficult grief response (Hoover, Markell & Wagner, 2004-2005). In this study the History of Sexual Abuse Group reported more deaths of family members and close others ($n = 12$) compared to the control group ($n = 7$), which could offer a partial explanation of why 40.74% of the former exceeded the threshold criteria on the affective/neurotic disorder. Research findings from Tsakanikos et al. (2007) noted an association between bereavement and psychopathology in people with ID. It is possible that many individuals in the History of Sexual Abuse Group are experiencing grief reactions/bereavement symptoms in response to the death of a significant other, which are often expressed as mood symptoms. Grief responses in intellectually disabled people are understood as often

manifesting differently from those of non-disabled general population. MacHale and Carey (2002), for example, reported on the behavioural expressions of grief in those with an intellectual disability that may often be mislabeled as challenging behaviours or symptoms of psychiatric disturbance. Similarly, Bonnell-Pascaul et al. (1999; as cited in McCarthy, 2001) found that grief in adults with ID was often associated with an increase in anxiety symptoms and maladaptive behaviour, with the anxiety symptoms abating over time. Other responses to loss that research has found in people with ID include increased stereotypical behaviour such as repetitive rocking, odd or bizarre behaviours (Hollins & Esterhuyzen, 1997; Bonnell-Pascaul, 1999, as cited in Sequira et al., 2003). Interestingly, Mitchell and Clegg (2005) suggest that children who are experiencing parental bereavement are at risk of PTSD because their sense of continuity and stability has been shattered. Certain behavioural reactions in children who have been diagnosed with PTSD, such as somatic complaints may be relevant in understanding how adults with ID respond to traumatic loss.

Age and life events

Some research has noted an association between age and being exposed to traumatic life events. In the present study, the History of Sexual Abuse Group on average was younger ($M = 18.59$ years) and experienced more life events ($n = 2.77$) compared with the control group who on average was older ($M = 29.12$ years) and experienced fewer life events ($n = 1.96$). These findings are similar to research by Hamilton, Sutherland and Iacono (2005), which showed that younger adults had a higher probability of experiencing traumatic life events. Similarly, Tsakanikos et al. (2007) also found a trend towards younger ages being more likely to be exposed to life events when compared with older age bands in the 12 months prior to being interviewed. This finding is interesting in that one may have associated increased age with possible exposure to more life events, however as seen above, the literature appears to contradict this.

5.2 The relationship between sexual assault and psychiatric symptoms

The History of Sexual Abuse Group obtained a high score for sexual problems ($n = 13$) in comparison with none of the control group reporting any sexual problems. Although

the PAS-ADD does not clearly outline what constitutes sexual problems, and whilst it is not known whether these sexual problems were present prior to the sexual assault, taking account of the fact that the History of Sexual Abuse Group has a younger mean age, it is possible that the sexual problems occurred subsequent to the sexual assault. Stravakaki (1997; as cited in McCarthy, 2001) noted that sexual difficulties were one of the prevailing symptoms of anxiety in people with ID who had experienced a traumatic event. Research conducted by Sequiera et al. (2003) found that being sexually abused was linked with elevated rates of psychiatric disturbance, problem behaviour and symptoms of post-traumatic stress.

A great deal of attention has focused on post-traumatic stress disorder (PTSD) in the general population and its high prevalence amongst people who have experienced a trauma. However, the impact of traumatic events on intellectually disabled individuals has not been a priority in research (Tsakanikos et al., 2007). Some of the common presenting features in people with ID who have been exposed to trauma include, anxiety, sleep disturbance, aggression and irritability (McCarthy, 2001), which are symptoms of PTSD that are similar to those found in the general population. A recent local study (Jasson, 2009) found an increased rate of PTSD symptoms in a sample of people with ID who had been sexually assaulted. Whilst the PAS-ADD Checklist does not measure PTSD symptoms, it is worth noting that, taking account of recent research findings, that PTSD often presents co-morbidly with other psychiatric disorders (McCarthy, 2001) and that when an ID person has experienced a trauma and presents with a subsequent change in behaviour or emotional state that they should be assessed for PTSD symptoms (Turk et al., 2005). In a sample of people with ID who had been diagnosed with PTSD Ryan (1994) (as cited in McCarthy, 2001) found major depression to be the most frequently diagnosed co-morbid condition. These findings were supported by Sequiera et al. (2003) who, whilst noting increased rates of depression, also found that there were increased behaviour problems in people with ID who had been abused. Locally, Kwendakwema's (2009) study looking at challenging behaviour in a sample of people with ID who had been sexually assaulted, reported increased rates of irritability, lethargy and hyperactivity in comparison with people who had no history of sexual

assault. It is important to take account of the developmental level of the person with ID as well as their cognitive and emotional capacity when looking at psychiatric symptoms (McCarthy, 2001) in that their responses to trauma often take the form of a change in behaviour.

5.3 Prevalence of psychiatric symptoms

In looking at the responses obtained on Section 2 of the checklist, the overall prevalence of psychiatric symptoms in the History of Sexual Abuse Group was 51.85%. These findings indicate a prevalence rate that is a great deal higher than those found in other studies using the PAS-ADD. For example, Deb et al. (2001), using the PAS-ADD, found an overall prevalence rate of 14.4%. Similarly Taylor, Hatton, Dixon and Douglas (2004) also using the PAS-ADD Checklist, found the rates of mental health problems to be 20.1%. These aforementioned studies included much larger sample sizes than the present study which may account for findings of lower prevalence rates. Taylor et al's. (2004) research using the PAS-ADD Checklist demonstrated lower response rates across the three subscales in comparison with this present study. In particular, 31.48 % of the overall sample in this study demonstrated affective/neurotic symptoms in comparison with 14 % of the sample in Taylor et al's. (2004) study.

The group with no known history of sexual abuse in this study scored lower than those with such a history on the affective/neurotic subscale. It is noted in the present study that the sample is predominantly female. Local and international research has shown that in general females have a higher rate of affective and anxiety disorders than males (Lunsky, 2003; Smiley, 2005; Stein, Seedat, Herman, Moomal, Heeringa, Kessler & Williams, 2008). A study by Hastings et al. (2004) conducted with ID participants also supported these findings and demonstrated that females demonstrated a significantly increased rate of affective and neurotic symptoms on the PAS-ADD Checklist in comparison with males. It is thought that that the participants' history of sexual trauma may also have contributed to an increased prevalence percentage on the affective/neurotic subscale and this may offer a partial explanation to the History of Sexual Abuse Group's high score on the affective/neurotic subscale. It is further considered that the higher rate of losses in the

History of Sexual Abuse Group may also have contributed to the increased affective and neurotic symptoms in the present study. Because no other local studies using the PAS-ADD Checklist have been done, it is difficult to make a comparison in the uniquely South African context. MacHale and Carey (2002) used the PAS-ADD Checklist and found that participants who were part of the bereaved group in their study scored significantly higher than the control group on the affective/neurotic disorder and organic condition but that there was no difference on the psychotic disorder. The results in this present study appear to have reflected similar findings between the groups with the History of Sexual Abuse Group experiencing more losses and obtaining significantly higher scores on the affective/neurotic disorder and the organic condition when compared to the control group. The considerably lower prevalence of symptoms of psychotic disorder reported in this study is in line with general research findings which indicate that these disorders are higher in hospital in-patients compared with those people living in the community (Taylor et al., 2004).

Significant questions on the PAS-ADD Checklist

As shown in the previous chapter, there were four questions on Section 2 of the checklist on which there was a significant difference between the two groups. The symptoms addressed by these questions include disrupted sleep, an increase in appetite, reassurance seeking behaviour and being mistrustful of others. The History of Sexual Abuse Group reported considerably more responses on these particular questions compared with the control group. Although it may be inferred that a large number of these symptoms are indicative of affective disorders, some of the research that has been conducted in the ID population has shown that several of these symptoms may in fact be linked with psychiatric disorders other than depression. Q 3, which focuses on broken sleep, is often understood as being a symptom of depression (DSM-IV TR, 2000) but research by McCarthy (2001) also shows that problems with sleep may be linked with more severe levels of ID.

Hurley (2006) notes that although few studies have focused on appetite as a symptom of mood disturbances in people with intellectual disability, it is a key indicator of affective

disorders. Q 8 on the checklist looks at increased appetite and whilst this is a symptom of major depressive disorder in the general population (DSM-IV TR, 2000), studies in people with ID have linked hyperphagia (continuous eating) with some genetic syndromes such as Prader-Willi syndrome (Gravestock, 2003). The development of the DC-LD for use in the ID population offers a category of psychogenic overeating which links overeating with stressors and this may be especially pertinent in individuals who have experienced many life events and who may be displaying distress through an increase in appetite. (Gravestock, 2003). Reid and Leonard (1977; as cited in Gravestock, 2003) found that binge-eating and cyclical vomiting were associated with epilepsy or affective disorder. It is interesting to note that in the History of Sexual Abuse Group that there is a higher number ($n = 7$) of individuals who are reported as having epilepsy in comparison with none in the control group, but there is not sufficient evidence to demonstrate a causal link between the two in the History of Sexual Abuse Group. It must also be held in mind that an increased appetite and weight gain are also well recognized side-effects of some psychoactive medications (Gravestock, 2003) and marginally more individuals in the History of Sexual Abuse group were reported as being on medication, but that a significantly larger portion of both groups did not take any medication.

The remaining questions Q11 and Q 12 both look at behaviour in interaction with others. Q 11 focuses on the degree to which the individuals may experience a loss of confidence in interacting with others which manifests in reassurance-seeking. Intellectually disabled people are often described as being over dependent in that they rely on others to help them and as such have a strong need for social reinforcement. It is thought that this factor may impact on their relationship with others who may experience this behaviour as burdensome. This finding is supported in literature which states that the ID population experiences a great deal more social rejection than the normal population (Zigler & Bennett-Gates, 1999). Bearing this in mind, it may be that the History of Sexual Abuse Group's high score on this question is partly due to the sexual trauma, with the reassurance-seeking resulting from high levels of fear and anxiety that the individual may be experiencing.

Q 12 looks at whether the individual is reported as being suspicious and untrusting. It is uncertain whether this behaviour is due to the sexual assault trauma or to one of the many potentially traumatic life events that had been experienced by the ID individuals in the History of Sexual Abuse Group. As has been previously discussed, people with ID often have communication difficulties and it may be that the suspicious, untrusting behaviour demonstrated by the History of Sexual Abuse Group may again be understood as a behavioural response to trauma. This is seen in research by Sequiera et al. (2003) who suggest that intellectually disabled individuals who have been sexually assaulted often presented with withdrawal from others, in particular 'seeking isolation from others, being preoccupied, resisting any form of physical contact and being listless, sluggish or inactive (p.454). In this research the group who had been sexually assaulted had a significantly higher score on this item than the control group, which is in line with problems such as difficulty trusting and hostility towards others that was found in international studies (e.g. Browne & Finkelhor, 1986, cited in Mansell, Sobsey & Calder, 1992; Greenwald et al., 1990, cited in Sequiera et al., 2003) This particular behaviour is similar to what is described in the DSM-IV TR (p.468, 2000) as a 'feeling of detachment or estrangement from others' that constitutes one of the avoidance/numbing symptoms of PTSD.

5.4 Informant reports versus self-reports

Within the ID population a third party is often relied upon to recognize symptoms of psychiatric illness and this often has a determining influence on whether the help-seeking and subsequent treatment process is put in motion (Moss et al., 1998). Reliance on informant information can sometimes be difficult in that they cannot be aware of the totality of an individual's internal subjective experiences or of non-visible autonomic symptoms that could be fundamental to making a correct diagnosis (Sequiera & Hollins, 2003). McBrien (2003) points out that agreement between self and informant report appear to be low for depression and that reports from informants are often subject to the preconceptions, psychological needs and beliefs of the informant as well as their tolerance levels. Interestingly, the presence of challenging behaviour is associated with a higher probability of case recognition (Moss et al., 1998; Jasson, 2009) and this is

thought to be because of the difficulties that maladaptive behaviours create for caregivers.

Although life events are generally considered by researchers as having a negative and stressful impact on individuals, this does not take into account how the ID individual who is experiencing the event perceives it. Some of these events, like moving home, may in fact be experienced positively by the person, which would then have implications for research and our understanding of how life events contribute to mental illness in intellectually disabled people (Esbensen & Benson, 2004). In the present study, the checklist was completed with caregivers who were not trained in detecting psychiatric symptoms or their clinical significance. It is important to note that the caregivers who were interviewed may not have been aware of or considered the myriad of ways in which the ID individual that they were reporting on may manifest difficulties. As such the caregivers may have missed reporting some symptoms or by the same token placed excessive importance on reporting certain symptoms which may impact on the reliability and validity of the findings. Whilst the checklist is designed to be used with lay raters Moss et al. (1998) do make suggestions that training the raters prior to administering the checklist would likely increase the reliability and validity of the results. It is important to note in this study, that the social workers from CMHS underwent training prior to administering the PAS-ADD Checklist as a way of encouraging consistency in administration procedures, which in turn was thought to improve the reliability and validity of the findings.

5.5 Implication of findings for the South African context

According to research conducted by Stein et al. (2008), the South African population has a high lifetime prevalence of psychiatric disorders. This country's pervasively high rates of violent crime, sexual and domestic violence expose people to a greater likelihood of experiencing trauma (Kaminer, Grimsrud, Myer, Stein & Williams, 2008) and this is also thought to contribute to the trajectory of mental illness in the country. South Africa's particular socio-political history also needs to be borne in mind when thinking about explanations for the high rates of psychiatric problems. In particular, some of the factors

implicated in these circumstances include racial discrimination, gender inequality, poverty and political and criminal violence. Research which has focused on developing countries has shown that they often have high rates of mental disorder and that this is closely linked with periods of rapid and unpredictable social change during which there is pervasive discrimination and unemployment (Patel & Kleinman, 2003). Research has consistently highlighted the association between ID and low socioeconomic status (Drews et al., 1995, as cited in Leonard & Wen, 2002) and shown that for children, growing up in a community which is characterized by racial segregation and poor resources (Breslau et al., 2001, as cited in Leonard & Wen, 2002) may impact more negatively on their IQ scores than familial factors. This country's socioeconomic history has impacted on different ethnic groups in varying ways. Stein et al. (2008), for example, reported that the Black population's disadvantaged socio-economic profile may increase their vulnerability to stressors and lead to higher rates of psychiatric disorders. Local research in fact supports this, such as Carey, Stein, Zungu-Dirwayi and Seedat (2003; as cited in Stein et al., 2008) who found high rates of depression, PTSD and somatisation disorders in a township primary healthcare clinic, while Rumble, Swartz, and Zwarenstein (1996; as cited in Stein et al., 2008), reported a prevalence rate of 27.1% of psychiatric morbidity in a local rural Coloured village, with the largest proportion of the cases falling into the categories of depressive or anxiety disorders. In the present study the majority of the sample consisted of individuals from the Coloured population, which is a historically disadvantaged socioeconomic group, and this alongside the majority of females in comparison with males may also be associated with the higher scores on the affective/neurotic subscale.

Poverty is also a factor which has been implicated in the etiology of psychiatric illness. According to Patel and Kleinman (2003) poverty and socioeconomic stress are regarded as the most important factors contributing to emotional distress. Alongside these factors, poor education or illiteracy has also been found to be a consistent contributing factor to mental illness. A lack of education often reduces people's opportunities to access resources which could improve their circumstances (Patel & Kleinman, 2003) and this is particularly true for the local ID population as there are few schools catering to the needs

of this population (Molteno et al., 2001). Another factor linked with poverty is that of sexual coercion, with intellectually disabled females being particularly susceptible to in the context of South Africa's high rates of sexual violence against women (Jewkes & Abrahams, 2002; Kaminer et al., 2008).

Although the field of ID has not been a priority in terms of healthcare and research, it is hoped that the findings of this study, which show similar trends to international research contribute to local knowledge about psychiatric problems in intellectually disabled people, although this is compromised by the difficulty in delineating the impact of different factors, including life events.

5.6 CONCLUSION

This study sought to investigate the existence of psychological problems in people with intellectual disability. This is an emerging field and until recently there has been little local research on this group of people and most of what is known comes from international studies. The PAS-ADD Checklist, one of the most commonly used assessment tools in studies on intellectual disability, was administered to caregivers of intellectually disabled people who were accessed through CMHS. This is an NGO that provides support to psychiatric and intellectually disabled individuals living in Cape Town Metropole. The sample consisted of two groups, one group had a history of sexual abuse while the other group had no known history of any sexual trauma. Overall findings showed those with a history of sexual abuse to have experienced more potentially traumatic life events, particularly financial problems and loss of significant others. It is not clear whether the loss of a significant other increased their vulnerability to sexual abuse or why they experienced more losses. In addition they scored higher on the affective/neurotic subscale, which is expected given trauma of sexual abuse. They obtained significantly higher scores on the possible organic disorder when compared with the control group and it is thought that the higher rate of epilepsy in the History of Sexual Abuse Group may have contributed to this. There were no significant differences

between the two groups on the psychotic disorder which is in line with findings generated from non-inpatient populations.

In terms of the implications of findings generated from this study, it is clear that the ID population experiences a high number of traumas and that this impacts on them psychologically. As has been noted, locally, the ID population is marginalized within the broader mental health sector which has huge implications for the provision of support services. The lack of local research conducted in the ID population is thought to contribute to the general lack of knowledge around prevalence rates of people with ID in South Africa as well as a limited understanding around potentially culture-specific responses to trauma in particular. It is thought that increasing the scope of research conducted in people with ID would generate evidence of findings which could be used by policy makers to create an awareness of intellectual disability.

The high rates of affective/neurotic symptoms within the sample as a whole are a cause for concern in that it seems apparent that no specific formal diagnostic and assessment process is currently available for people with ID. This in turn means that there is a general reliance on caregivers to notice any changes in behaviour and symptoms that the ID individual may begin to exhibit. This is problematic in that individuals with ID are a particularly vulnerable population who are at risk for being exposed to trauma and this coupled with a reliance on caregivers who are not formally trained is thought to increase the risk of potential responses to trauma and psychiatric symptoms going undetected in the person with ID. Caregivers and members of the community need to be aware that people with intellectual disability may not always verbally disclose a traumatic incident and therefore any challenging or maladaptive behaviour that an individual with ID exhibits should not just be understood as being part of the intellectual disability but may be symptomatic of a response to trauma.

There are several limitations of this study. The instrument which was used in this study, the PAS-ADD Checklist is limited in terms of what it is able to elicit. This instrument has generally been found to be over-inclusive and although this is noted as being a favourable

characteristic of checklists it only elicits psychiatric symptoms and does not in itself provide a definitive psychiatric diagnosis. In terms of Section 1 which covers the life events, a clear description of what constitutes some of the events is unclear and this leaves interpretation of the question open to both the caregiver and the interviewer. This does not allow the researcher to delineate the nature of the impact of particular life events on the particular ID individual. Also, whilst Section 2 covers broad areas of psychiatric symptoms, there are definite gaps especially around epilepsy which can impact significantly on an individual's psychological functioning. The checklist as such was developed in the United Kingdom and is not cross-culturally validated and it does not account for culture specific psychiatric symptoms which may exist in the South African setting. Because there is no gold standard diagnostic tool for use in the ID population either internationally or locally, it is uncertain what the symptoms that were elicited may specifically present. Previous research which has been conducted serves as the only benchmark against which to compare the findings which may make an understanding of atypical symptoms which are elicited particularly difficult.

In terms of the sample, a limited number of participants were included because of time and financial constraints. There was also possible bias in the sample selection as the control group was selected by the social workers. Although it was requested that the control group be chosen to match the group with a history of sexual abuse as closely as possible with regards to demographics it is not known on why the social workers chose to select particular individuals. This has implications for the generalisability of findings to the ID population as there may be unknown variables which may also have impacted on the responses of the participants which may also impact further on the overall findings. Also, it is not known whether the reported symptoms are due to the sexual abuse or not. The social conditions in which the individuals in the sample live are bad and people are exposed to trauma all the time. But, since an attempt was made to match the control group, one may speculate that the sexual abuse seems to contribute to more psychological distress as shown by the symptoms reported.

There are also potential biases inherent in using caregivers as respondents as they are not generally trained to detect psychiatric symptoms and this may impact on what they report. The impact of using caregivers as respondents has also been considered and is thought to impact to a degree on the responses obtained. Although using caregivers as respondents serves as a useful source of information, they are not able to know everything about another individual. Whilst the caregivers were interviewed in this particular study, it is thought that making use of assessment tools specifically designed for people with ID, may provide researchers with a first-hand experience of the difficulties which these individuals experience. Although people with ID may have communication difficulties, many, especially within the mild and moderate range are still able to talk and it may be that simplifying questions and making use of the DC-LD would allow researchers to obtain unmediated communication from the ID individual.

In making recommendations for future research, based on the findings from this research it is clear that more research needs to be undertaken within this field. As such, this study attempted to provide a starting point for further research in the ID population. Its focus on the prevalence of psychiatric symptoms demonstrated that the sample of individuals used in this study are reported as having varying rates of psychiatric symptoms and that this is becomes more prevalent when individuals have been exposed to traumatic life events, especially sexual assault. It is not known whether individuals with ID generally experience more potentially traumatic life events than the general population in South Africa. Whilst it was previously mentioned that it was difficult to determine the varying impact of the particular events on the development of psychiatric symptoms in these individuals, it is thought that this observation may offer an opportunity for further research to focus more closely on the impact of life events on the ID population. It would also be significant to study the atypical symptoms presented by this sample and observe whether future research offers similar findings which in turn could impact significantly on the diagnostic process of affective disorders in the ID population.

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APPENDIX A

UNIVERSITY OF CAPE TOWN



Child Guidance Clinic

University of Cape Town Chapel Road
Rosebank 7700, Cape, South Africa
Telephone (021) 650-3901
Fax: (021) 689-1006
E-mail: Nokuthula.Shabalala@uct.ac.za

Informed consent for participants in Master's Study

Purpose of the study:

I, Aimee Jasson, am a MA (Clinical psychology) student at the Psychology Department at the University of Cape Town. As part of a research project in association with Cape Mental Health Society, this study aims to explore the manifestations or symptoms of psychological distress deriving from sexual assault within people with intellectual disability.

The research is supervised by Dr. Nokuthula Shabalala, Director, Child Guidance Clinic, University of Cape Town.

What happens in the study?

If you agree to be interviewed, you will be asked to take part in a semi-structured interview in which various aspects of the individual's experiences is either self reported or reported by their legal guardian / care taker.

- Your identity will not be revealed at any stage during the research or in any documents that will emerge from the study.
- Confidentiality will be maintained at all times. Your responses will not be divulged to anyone not directly involved in gathering or analysing the data.
- This will be a once-off interview that will not last longer than 1½ hour.
- You will be asked some questions but you have the right NOT to answer any question that makes you uncomfortable.
- As legal guardian / caretaker, you have the right to consider the autonomy of the person with intellectual disability and their right to assent or dissent to the interview should be upheld and respected.
- You have the right to terminate this interview at any time if you choose to, or even withdraw from participation without any penalty.

The risk to you as participant may be:

- Discomfort with the topic.
- Anxiety because of the interviewing process.
- Physical and emotional tiredness because of the interviewing process.
- Re-traumatization because of the topic.

The benefits to you as participants may be:

- The opportunity to share your own experiences of the incident.

This is not the psycho-legal appointment arranged by the South African Police Service with Cape Mental Health Society, and you would still need to attend this appointment in due course. However, some of the information will be passed on to the Cape Mental Health clinician, e.g. the effects of /reaction to trauma. The researcher is also legally bound to break confidentiality in the following instances: where the participant is a suicide risk, where the participant is a risk to others and where child abuse is present or if subpoenaed by the Government.

If you have any queries about the research or your participation, please contact me at 0847399066 or ajasson@hotmail.com. The contact details for Dr. Shabalala is as above.

STATEMENT OF UNDERSTANDING

I, _____, understand all the above-mentioned information and voluntarily agree to the research.

Participant's signature: _____

Guardian's / Caretaker's signature: _____

Contact number: _____

Date: _____

Place: _____

Person obtaining consent: _____

University Of Cape Town

APPENDIX B

SECTION 2 BEHAVIOURS

		IN THE LAST FOUR WEEKS			
Question	Has not happened, or has always been like this	Happened occasionally or present in a mild form	Happened frequently, or present in a moderate form	Present in a severe form for much of the time	
1	Less able or less prepared to use self-care skills, such as dressing, bathing, using the toilet and cooking	0	2	2	2
2	More forgetful or confused than usual, eg forgetting what has been said, or getting lost in familiar places	0	2	2	2
		SCORE A =			
3	Broken sleep , waking up for an hour or more, before falling back to sleep	0	0	1	1
4	Less able to concentrate on chosen activities such as watching television, reading or other hobbies	0	0	1	1
5	Restlessness or pacing, unable to sit still	0	0	1	1
6	Irritable or bad tempered	0	0	1	1
		SCORE B =			
7	Loss of appetite and enjoyment of food (If this is known to be due only to dieting or bodily illness, rate as not present)	0	0	1	1
8	Increased appetite, over-eating	0	0	1	1
9	Change of weight, enough to make clothing fit less well. (If this is known to be due only to dieting or bodily illness, rate as not present)	0	0	0	0
10	Startled by sudden sounds or movements	0	0	1	1
11	Shows loss of confidence with other people, such as repeatedly asking for	0	0	1	1

	reassurance				
12	Suspicious, untrusting, behaving as if someone is trying to harm them or is talking about them	0	0	1	1
13	Avoids social contact more than usual for the person	0	0	1	1
14	Loss of self-esteem, feeling worthless				
15	Delay in falling asleep-at least one hour later than the person's usual time	0	0	1	1
16	Waking too early (at least one hour before the person's usual time) and unable to sleep again	0	0	1	1
SCORE C =					
17	Loss of interest and enjoyment, such as spending less time doing things that the person likes to do	0	0	2	2
18	Sad or 'down' (noticed for at least three days in the past four weeks)	0	0	2	2
19	Sudden intense fear or panic triggered by situations or things, such as being alone, crowds, thunder, etc	0	0	2	2
20	Fearful or panicky (not triggered by situations or things)	0	0	2	2
21	Repeated actions, such as checking over and over that a door has been locked, or having to do things in a particular order	0	0	2	2
22	Too happy or 'high' (noticed for at least three days in the past four weeks)	0	2	2	2
SCORE D =					
23	Strange unshakeable beliefs which are impossible or untrue eg believing they have special powers, or that something is controlling their mind, or that someone is trying to harm them	0	2	2	2
24	Strange gesture or mannerisms, eg body rocking, hand flapping	0	1	1	1
25	Strange use of language, eg talking much faster than usual, repeating the same phrase many times, or	0	1	1	1

'echoing' the speech of others

SCORE E =

APPENDIX C

Question	Null hypothesis	Test	Significance	Decision
1	The distribution of Q1 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.315	Retain the null hypothesis
2	The distribution of Q2 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.407	Retain the null hypothesis
3	The distribution of Q3 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.023	Reject the null hypothesis
4	The distribution of Q4 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.315	Retain the null hypothesis
5	The distribution of Q5 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.065	Retain the null hypothesis
6	The distribution of Q6 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.115	Retain the null hypothesis
7	The distribution of Q7 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.303	Retain the null hypothesis
8	The distribution of Q8 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.019	Reject the null hypothesis
9	The distribution of Q9 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	1.000	Retain the null hypothesis
10	The distribution of Q10 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.086	Retain the null hypothesis
11	The distribution of Q11 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.037	Reject the null hypothesis
12	The distribution of Q12 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.011	Reject the null hypothesis
13	The distribution of Q13 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.195	Retain the null hypothesis
14	The distribution of Q14 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.229	Retain the null hypothesis
15	The distribution of Q15 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.229	Retain the null hypothesis
16	The distribution of Q16 is the same across categories of Groups	Independent samples-Mann-Whitney <i>U Test</i>	0.680	Retain the null hypothesis

17	categories of Groups The distribution of Q17 is the same across	Whitney <i>U Test</i> Independent samples-Mann- Whitney <i>U Test</i>	0.195	Retain the null hypothesis
18	categories of Groups The distribution of Q18 is the same across	Whitney <i>U Test</i> Independent samples-Mann- Whitney <i>U Test</i>	0.718	Retain the null hypothesis
19	categories of Groups The distribution of Q19 is the same across	Whitney <i>U Test</i> Independent samples-Mann- Whitney <i>U Test</i>	0.185	Retain the null hypothesis
20	categories of Groups The distribution of Q20 is the same across	Whitney <i>U Test</i> Independent samples-Mann- Whitney <i>U Test</i>	0.642	Retain the null hypothesis
21	categories of Groups The distribution of Q21 is the same across	Whitney <i>U Test</i> Independent samples-Mann- Whitney <i>U Test</i>	0.229	Retain the null hypothesis
22	categories of Groups The distribution of Q22 is the same across	Whitney <i>U Test</i> Independent samples-Mann- Whitney <i>U Test</i>	0.344	Retain the null hypothesis
23	categories of Groups The distribution of Q23 is the same across	Whitney <i>U Test</i> Independent samples-Mann- Whitney <i>U Test</i>	0.303	Retain the null hypothesis
24	categories of Groups The distribution of Q24 is the same across	Whitney <i>U Test</i> Independent samples-Mann- Whitney <i>U Test</i>	1.000	Retain the null hypothesis
25	categories of Groups The distribution of Q25 is the same across	Whitney <i>U Test</i> Independent samples-Mann- Whitney <i>U Test</i>	0.498	Retain the null hypothesis